

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

FALL/WINTER 2005
VOLUME 7 ISSUE 2

People with HIV
tell all about life
between the sheets

SEX MATTERS

Plus expert advice
on how you can
spice it up

RESISTANCE TESTING
CARING FOR YOUR KIDNEYS
NATURALLY HEALTHY



Canadian AIDS Treatment Information Exchange
Réseau canadien d'info-traitements sida



LAST SPRING, on CATIE's behalf, I went on a treasure hunt. CATIE hosts a working group of community members from across the country who produce and distribute HIV treatment information. This group—the Treatment Information Network, or "TIN" (because everything AIDS must have an acronym)—meets regularly to carry out joint activities that make everybody's work more efficient.

Although Canadian AIDS service organizations (ASOs) widely share materials with each other, we felt that some great resources were slipping through the cracks. We wanted to (a) gather a larger pool of resources to share and use, and, (b) flag what is missing and most needed, as a kind of map for developing new materials. So we called up agencies from coast to coast and asked: "What do you use? What *could* you use?"

We gathered quite a collection. Many of the materials are well known and widely used—we've highlighted some in previous issues. For this *Positive Side*, we present a few new jewels for you.

STREET DRUG INTERACTIONS

When asked for their wish list, many ASOs said they need the dirt on drug interactions—specifically between street/recreational drugs and HIV meds. This info may seem hard to come by, but it is out there. Look no further:

Medical Drug Interactions with Street Drugs: A resource by and for drug users. Not Canadian, but this little gem of a pamphlet from **Needle Exchange Emergency Distribution (NEED)** in Berkeley, California, is written in seriously street-smart, no-BS language—something drug users can relate to. For an online version: www.berkeleyneed.org (click on "resources").

For more technical info, the **Toronto Hospital Immunodeficiency Clinic** has produced extensive lists of drug interactions, including **Postulated Interactions with Recreational Drugs**. To find out how HIV meds mix with rec drugs—from alcohol to THC—go to www.tthivclinic.com (click on "Drug Interaction Tables" under "Medical Information for Health Care Professionals"). These lists contain a lot of dense data—you may want to flag them to your health care provider or local ASO.

Don't forget CATIE's own harm-reduction how-to for drug users: **pre*fix: harm reduction for + users**. Loaded with useful, user-friendly info—from safe shooting to co-infection to pain management—it's available in English and French at www.catie.ca or by calling 1.800.263.1638.

NEWLY DIAGNOSED?

When someone's just been diagnosed with HIV, well . . . you may know how it feels. The needs of newbies are widely varied, but at some point most people want a standard "now that you're positive" reference guide. The challenge is finding the "Goldilocks" version—not too much info, but not too little. Since we all have our own idea of what's just right, it's good to have a few

options to choose from. Many respondents cited CATIE's bilingual **Managing Your Health** as their "bible"—the must-have resource for every PHA's shelf. Here are a couple of other care guides specifically for Canadian HIV newbies:

The HIV Care Program at **Windsor Regional Hospital** offers up **Think Positive: A Guide to Healthy Living**. This six-module booklet covers lots of self-care issues, with significant sections on the medical aspects of HIV infection, treatment and managing health problems. At 38 pages, it's easy to swallow. Go to www.wrh.on.ca (under "Programs & Services" click on the "HIV Care Program"), e-mail hivprogram@wrh.on.ca or dial 519.254.6115.

Opening Doors to Self Care, from the **Conception Bay North AIDS Interest Group** in Newfoundland, is a very approachable guide to diagnosis, medication, nutrition, emotional care and more. If I could turn back the clock to when I was diagnosed, this book would have been a real comfort, with its personal anecdotes and gentle, reassuring tone. At 116 pages, it's thorough but not daunting . . . plus, there's a recipe for stuffed moose steak! A new printing is due out in late 2005. To read some excerpts, go to www.cbnaig.org/fourthpage.htm and click on "Self-Care Manual." For copies, contact CBNAIG at bn.aids.intgr@nf.sympatico.ca or 1.877.596.4433 (you'll need to pay for postage).

ABORIGINAL PEOPLES WITH HIV

Chee Mamuk, the Aboriginal program of the B.C. Centres for Disease Control, has produced several series of extremely readable and highly informative pamphlets on HIV—with words and images that speak to First Nations peoples. The **Aboriginal HIV Pamphlet Series** and the **Women's HIV Pamphlet Series** can be found at www.bccdc.org (under "Resources," then "Brochures & Pamphlets") or by calling 604.660.0584 (you'll need to pay for the pamphlets and postage).

Drug coverage can be a bewildering tangle of red tape. The **Canadian Aboriginal AIDS Network (CAAN)** offers a bilingual guide to drug and health care coverage. **HIV & the Non-insured Health Benefits (NIHB) Program for Aboriginal People in Canada** is a practical guide to native health coverage that includes notes on variations between provinces. Find it online at www.caan.ca (click "Resources," then "Fact Sheets") or call 1.888.265.2226.

FRENCH LANGUAGE

Most of us are familiar with the wonderful array of fact sheets from the folks at the New Mexico AIDS InfoNet. Current and concise, they're available in English and Spanish at www.aidsinfonet.org. Now, **CPAVIH** has started to adapt and translate key **fact sheets from the New Mexico AIDS InfoNet** into French. To date, fact sheets on several anti-HIV meds, lab tests and side effects are available in plain text and PDF format on CPAVIH's website at http://cpavih.qc.ca/cpavih-new/inf_doc_en_ligne/feuill.

Note: If you cannot access online documents, call CATIE toll-free at 1.800.263.1638. Staff will print and send the document to you.

—compiled by Derek Thaczuk

EDITOR'S LETTER

Dim the lights and let your hair down. It's time to get up close and personal and tell the truth about sex—what we do and what we don't, what we want to do and what we can't. With its holistic look at life with HIV, *The Positive Side* touches on *all* the aspects of our health that need nurturing: physical, mental, emotional, spiritual—and sexual.

CATIE's own Darien Taylor ignites the sex talk with an essay about sexual trials and tribulations among people living with HIV/AIDS (PHAs). Also part of the package, four brave PHAs—two of whom are on the cover—speak openly about their pre- and post-diagnosis sex lives. "Brave" because though many PHAs have experienced sexual problems, most are reluctant to talk about it. Finally, experts from a variety of fields reveal their knowledge about sexual dysfunction and offer some terrific tips for a good, healthy sex life.

Also in this issue: Carol Major delves into drug resistance testing to explain this rather complicated business. Read this "pièce de resistance" and find out when it's important to be tested and what the results can—and can't—tell you. Diane Peters gives a nod to naturopathic medicine and describes how this complementary therapy can help you manage your health. And Maggie Atkinson shares what she learned about kidney health after starting a new antiretroviral with potential kidney side effects. She did the research so you don't have to! Also, poet and activist River Huston teaches us all a thing or 10 about her positive posse.

It sure was a challenge to find women to interview for this issue (Chatty CATIE features five men!). So here is a shout-out to the positive women: We want to hear from you!

All of us here at *The Positive Side* are excited to announce that we now exist in a whole new dimension—online! This means that we can give you more ways to enjoy the magazine. Forwarding a copy of a favourite article just got a whole lot easier, too. So did sending a letter to the editor. What do you think about this issue? What would you like to read about in upcoming issues? We look forward to your comments.

Visit the site at www.positiveside.ca. See you there . . .

—RonniLyn Pustil

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Resources

Community Chest: Check out these gems

By **Derek Thaczuk**

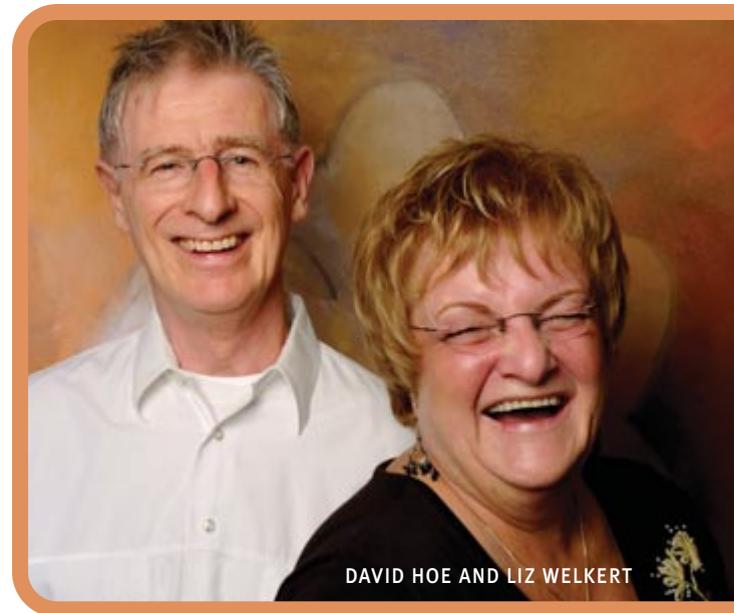
10 Things You Don't Know
about HIV+ Women

River Huston speaks out on
behalf of her positive posse

Chatty CATIE

5 PHAs praise their "other"
health care providers

Interviews by **RonniLyn Pustil**



DAVID HOE AND LIZ WELKERT

Sexual Healing

Have you lost that loving feeling?
4 PHAs talk about life between the sheets;

8 experts offer tips on spicing it up
Essay and interviews by **Darien Taylor**

Resistance Assistance

The ins and outs of HIV drug resistance testing
By **Carol Major**

When Nature Calls

The role of naturopathic medicine
for people with HIV

By **Diane Peters**

Here's Lookin' at You, Kidneys

HIV and kidney disease—
what you need to know

By **Maggie Atkinson**

Pottery Barn

Henry "Blake" Hiebert
on why he kneads clay

HIV Positive? Supporting someone who is?

CATIE is here for you.

In print, online and over the phone

The Canadian AIDS Treatment Information Exchange is Canada's national provider of treatment information in English and French to people living with HIV/AIDS, their care providers and community organizations.

CATIE is committed to improving the health and quality of life of all people living with HIV/AIDS in Canada, by providing accessible, accurate, unbiased and timely treatment information. Here's what we offer:

■ FREE ONE-ON-ONE PHONE SESSIONS

1.800.263.1638

Speak anonymously with one of our trained Treatment Information Service Representatives about your treatment questions. Find out about local resources anywhere in Canada.

■ FREE E-MAIL INFORMATION

questions@catie.ca

Ask any HIV/AIDS treatment questions of our knowledgeable staff when it is convenient for you and we'll respond with the information, resources and links you need.

■ CATIE WEB RESOURCES

www.catie.ca

Read or download treatment publications, current news and CATIE's many other resources. Plus, check out our links to other useful Internet sites.

CATIE Publications

To order any of our materials (in English or French) or to become a subscriber of *The Positive Side*, please contact us at **1.800.263.1638** or download an order form from our website at **www.catie.ca**.

A Practical Guide to HAART: Up-to-date, reliable information on the various aspects of treatment, including a description of the virus and the immune system, the stages of HIV disease, the tests used to assess health status, and anti-HIV medications. A very useful guide.

A Practical Guide to HIV Drug Side Effects: What you need to know about various side effects related to treatment, from appetite loss to sexual difficulties, and tips for countering or preventing them.

A Practical Guide to Complementary Therapies for People Living with HIV/AIDS
An overview of many alternative therapies used by people living with HIV/AIDS, including massage, mind-body medicine and complementary medical systems such as Ayurveda and homeopathy. Includes lists of resources where you can find more information about various therapies throughout Canada.

A Practical Guide to Herbal Therapies for People Living with HIV/AIDS

An essential reference tool for people living with HIV/AIDS seeking information on understanding, using and choosing herbal medicines.

Fact Sheets/ Supplement Sheets: Concise, credible overviews of a wide variety of specific conditions, symptoms, medications, side effects, complementary therapies, vitamins and other treatment issues of interest to people living with HIV/AIDS.

Managing Your Health: A must-read guide for people living with HIV/AIDS which addresses social, legal, health-related and practical issues comprehensively and from a national perspective. An outstanding primer.

pre*fix: A harm reduction booklet for HIV+ drug users.

BECOME A CATIE MEMBER

More and more people and organizations are joining CATIE. Join now to receive updates on treatment information by e-mail or regular mail.

Visit **www.catie.ca** or phone **1.800.263.1638** to join.

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IMPORTANT: Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV-related illness and the treatments in question.

The Canadian AIDS Treatment Information Exchange (CATIE) in good faith provides information resources to help people living with HIV/AIDS who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

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Disponible en français aussi

10 Things You Don't Know about HIV+ Women

River Huston
speaks out on behalf
of her positive posse



THERE ARE SO MANY ASSUMPTIONS about women with HIV: for example, that we're easy, addicts or have real poor judgment when it comes to picking a partner. Some and all of that may be true for some of us, and so what? The point is, like any group, we are individuals falling under the category of HIV positive women. We come from every walk of life, ethnicity, religion and socio-economic background—which makes each story unique. One thing that's clear is that HIV is a medical problem and not an adjective to describe who any of us are.

1 We are not heroes, courageous or brave. We're just trying to get through life the best way we can.

A hero is someone who runs into a burning building to rescue a wheelchair-bound woman or dives into the water to save a child from drowning. I've been called a hero, courageous and brave from the beginning, but really I've found that every woman I've met who lives with HIV and doesn't let it define, destroy or devastate her life is just a strong woman living her life to the best of her ability. When you make me the hero you put me on a pedestal I am sure to fall off of.

2 We can still have great sex.

But first I have to recover from everything they say is safe sex. Starting with the female condom, by the time

you get this thing in, you don't want sex—you want a Valium. Only second to that atrocity is the dental dam and I really don't need someone to use a latex glove to touch me. There is so much more to sex than conventional intercourse and oral sex. In the long run, my sex life has improved because I've learned to communicate by talking about safe sex and exploring other options such as toys, fantasy and outfits.

3 We can have a full life including a career.

This is a choice I can make. Treatment access has made it possible for me to have a future with plans that include long-term career goals.

4 We can give birth to HIV negative children.

Medical knowledge has greatly reduced the chances of passing on the virus to my children and has given me the strong possibility of watching them grow up and become adults.

5 We are not the face of AIDS.

I do not have to be the poster child for a disease. Whether I disclose publicly or not, I am not defined by my illness. HIV is a virus and I am much cuter than that.

6 We still want romance.

I need to be treated with respect, adoration and gifts. HIV did

not erase my desire to be wooed and romanced.

7 We can be with an HIV negative partner.

Most people assume that my husband must be HIV positive. I've got news for them: He is negative and HIV plays such a minor role in our lives. Positive women do not rule out being with a positive partner but we don't have to be limited solely to that population.

8 We can live in the moment.

HIV is not a gift; if it is, get me to the return department. But it has given me the insight to not dwell on the past or worry about the future. We are all going to die someday. I've been given the urgency of living each day to the fullest, so I don't spend them thinking about the music I want played at my memorial service.

9 We do not have to settle.

I am not damaged goods. I am an amazing, sexy, smart and attractive woman. I can choose who it is I want to be with. I do not have to be with someone who treats me poorly, does not have a job or a future or is just a poor match because I think no one else will be with me.

10 We are happy.

Being HIV positive does not have to intrude on my happiness. My birthright is a life of joy. Once I made peace with the fact that "I have a virus in my blood that causes trouble but for many of us can be managed" I could get on with my life, which includes lots of laughter, friends, family and contentment. I am in the bonus rounds of life and loving every magnificent minute. +

River Huston is an award-winning poet, journalist and performer. She is the author of five books, including *A Positive Life: Portraits of Women Living with HIV*. She is currently performing her one-woman show, *Sex, Cellulite and Large Farm Equipment: One Girl's Guide to Living and Dying* across the United States. For more info, go to www.riverhuston.com.

Doctor Who?

Do you swear by your naturopathic doctor? Would you go mad if your psychotherapist retired? Is your massage therapist the best thing since sliced bread? We asked five PHAs: Who, besides your HIV doc, is your most valued health care provider? Read all about the “other” health professionals in their lives.



DARRELL MARTIN

“My therapist is a real confidence builder.”

therapist has a way about her that’s very sweet and caring, but there’s no beating around the bush. She’s very direct and she challenges me in a good way. She gets me to where I need to go, if I choose to.

For the longest time, I didn’t trust anyone. I was cynical, bitter and defensive. I had a lot of negativity in my life regarding my HIV status. When I was diagnosed at 25, my life basically stopped. I was downtrodden and started getting involved in bad relationships. I felt suicidal. I was keeping secrets and held a lot of guilt and shame. My therapist has helped me let go of that and learn to move on. She’s helped me heal some of my wounds.

I met my therapist through my partner. He suggested I see her because our relationship was falling apart. Actually, I was falling apart and getting into situations that weren’t good for me. So, I gave her a call and I’ve been seeing her ever since. Now I talk more with my partner about my emotions and feelings.

Therapy has made me feel better about myself. My therapist is a real confidence builder. I’ve learned to have some self-worth and self-esteem. It’s really helped me get out there and do some great stuff. I’d never shown my artwork before because I never had the confidence, but last week I had my first show, which was great.

At the end of the day, you have a choice: You can live or you can die. I’m choosing to live. Now I’m starting to see the light at the end of the tunnel and I never thought I would.

ROD MICHANO, 41

Public speaker/HIV educator, Toronto

Diagnosed with HIV: 1987

www.redskyhealing.com

My **traditional healer** has helped me understand more about my illness by applying it to an Aboriginal context and relating HIV to the medicine wheel teachings. I started traditional healing in 1996. One day, my cousin back

DARRELL MARTIN, 38

Artist, New Glasgow, Nova Scotia

Diagnosed with HIV: 1991

I’ve been seeing my **psychosynthesis therapist** every other week for the past year. I think mental health plays a big role in someone who has an illness. Your psyche is very important. It affects everything about you.

A psychosynthesis therapist is someone who really gets inside you and brings you out. She doesn’t just nod her head and take notes. She gestures and makes eye contact. We share, grieve and talk about pain. Sometimes we do meditation and breathing. During meditation the sound of her voice and what she’s saying bring all these emotions to the surface. She says there’s no reason to feel afraid, intimidated or ashamed to let my emotions show—if I feel like screaming, crying or swearing, I should let it out. It really makes me feel so much better.

Our sessions are in her living room. I sit on the couch, there’s a fireplace and it’s a very relaxing, inviting environment. Another plus is that she’s a woman. I get along with women better than men. I find a woman therapist very nurturing. I’ve had male therapists and there always seemed to be tension and conflict and some level of homophobia.

I’ve seen other therapists before but they didn’t do a whole lot for me. I had so much bottled up inside and wasn’t able to bring it out. I’d belly ache over minor situations and not get to the root of the problem. My current



home in Pic River, Heron Bay, got a spiritual message from my sister who had passed to the spirit world. My sister told her that I needed help, as I was beginning to get very ill. The next day, my cousin called and asked how I was. She mentioned that a traditional healer, Diane Longboat, was coming to Pic River.

I went there and offered her tobacco—one of the four most sacred medicines Aboriginal people use. By offering tobacco, you're giving respect to our culture, to Mother Earth and to the Creator for allowing us to have this day. Diane explained that my cousin told her I have HIV. She was going to give me my traditional name through a ceremony, as part of my healing. Your traditional name comes from the Creator. It came to Diane right away—Shining Thunderbird Eagleman.

Diane doctored me and looked me over. She told me I needed to go to the sweat lodge. Days later I went to my first sweat lodge ceremony. My aunt was praying outside. She said when I went in I looked like an old, sickly person, but when I came out about an hour later, I looked reborn. I *felt* different, like I was alive again. Before I went into the lodge, I had no appetite, I could barely sleep, I had headaches all the time. After I came out, I had a feast. My headaches were gone and for the first night in ages I had a good sleep.

Soon after, I got very sick. I wound up in Casey House for six months, wasting and bedridden, and didn't go to the sweat lodge at all. I started combination HIV therapy and got horrible side effects—you name it, I got it—so I had to stop. The meds were really doing a number on my liver. But when I combined the Western medicine with traditional healing, I stopped getting the side effects. Using the sweat lodge and doing traditional medicine to detoxify and cleanse my body allowed me to take the meds again. Now I'm undetectable and experience very few, if any, side effects or illness.

I go to the sweat lodge once a month. My partner and I attend a lodge in Toronto



“The sweat lodge has gotten me through a lot.”

specifically for Two-Spirit people, with Wanda Whitebird, a traditional counselor at Anishnawbe Health Toronto (416.360.0486).

If I didn't have the lodge, I really think I wouldn't be here today. The sweat lodge has gotten me through a lot. It's like being back in your mother's womb. You're cleansed—it takes out all the toxins, especially after you're doctored by a traditional healer.

RANDY SAMPERT, 34

Chairperson of Living Positive, Fort Saskatchewan, Alberta
Diagnosed with HIV: 2002

My most important health care provider is my **general practitioner** (GP). When I moved back here from Vancouver last year, my original GP had lots of experience with HIV. But, unfortunately, he passed away last February, so I had to find a new GP while dealing with HIV and Kaposi's sarcoma cancer.

I interviewed one doctor who was taking on new patients. We discussed the issues I was facing and I gave him a brief medical history. I was his first patient with HIV. In that meeting, he said, “It sounds like you'll be a challenge to work with, but I'm up for it.” And he has been.

There was a lot I needed to learn in terms of understanding the lab work, drug interactions and potential side effects. My GP and I were learning about all this at the same time. We discussed potential medications that could help me deal with peripheral neuropathy side effects. I would sometimes bring him information that I found while researching on the Internet and we'd discuss different options. He finally put me on amitriptyline to reduce the pain from the neuropathy. This drug has started to give me back some of the quality of life that I'd lost.

My GP is a compassionate doctor who spends extra time listening and talking to me, as he knows I've struggled with depression. He's there to help and support me until I can get to see my psychologist. While

applying for medical disability I was feeling quite depressed, and the overwhelming bureaucracy led to further depression. As usual, my GP was there for me to lean on.

After a year of chemotherapy, I am considered to have the cancer in remission. I can now get my life back in order.

BRADFORD McINTYRE, 53

AIDS awareness educator, Vancouver
Diagnosed with HIV: 1985
www.PositivelyPositive.ca

Along with my GP and AIDS specialist, my **naturopathic doctor** (ND) is a valued partner in addressing my health issues. My ND spends a great deal of time with me explaining my health condition and he gets to the root cause of the problem. Often, he has answers for me where my medical doctor does not!

It is important to understand the immune system and what it needs to be able to carry out its functions. It's necessary to have knowledge about the cells, nutrients and what the cells require to be up and running to maximum capacity. The digestive system and organs all have their own needs to be met. My ND teaches me and emphasizes specifics in diet improvement and healthy lifestyle changes and approaches, which recognize the importance of a healthy body, mind and spirit. There are few other physicians who are able to take the necessary time with me.

Recognizing the ability of the body to heal has prompted many people to choose a naturopath. My ND has played an important role in addressing diarrhea, nausea, neuropathy, irritated skin and rashes, wasting, fatigue, loss of appetite, and immune suppression. With the aid of homeopathic remedies and vitamin replacement therapies provided by my ND, I have successfully boosted my immune system, reduced drug side effects and increased the efficacy of the HIV drugs. The neuropathy and my quality of life have improved in numerous ways! +

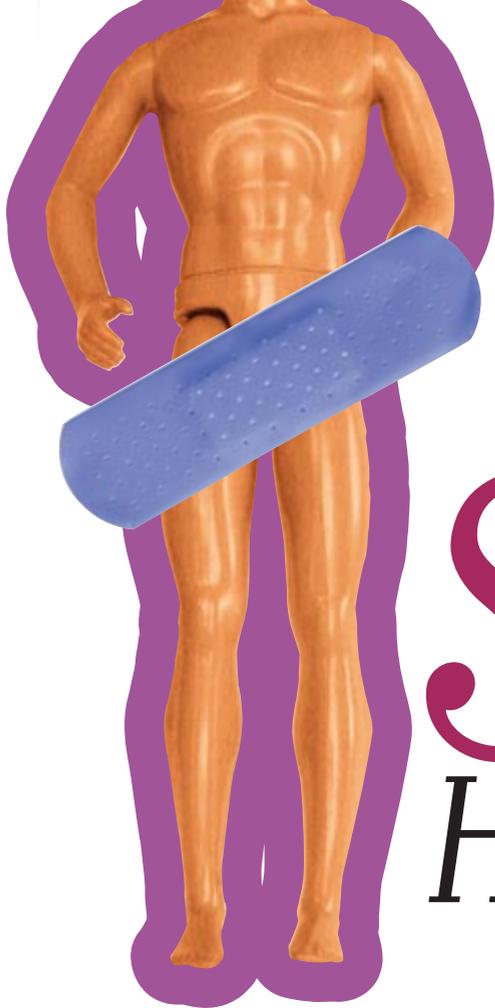


“My naturopath gets to the root of the problem.”

BRADFORD MCINTYRE

“My GP was there for me to lean on.”

RANDY SAMPERT



*Have you lost that
loving feeling?*

Sexual Healing

BY DARIEN TAYLOR

SEXUAL DYSFUNCTION: IT IS THE elephant in the HIV clinic waiting room. We all know it's there (not *moi*, of course!), but we don't want to talk about it. And why not? At some deep, dark level of our psyche, do we feel guilty about having sex? In spite of all the efforts to make safer sex sexy, do we still have fears about infecting our loved ones? Do we feel that we should just be grateful that we're alive? Or does the cheery sex-positiveness we're supposed to maintain make it hard to admit that being positive makes us feel negative about ourselves, sexually speaking?

How we express ourselves sexually is an essential part of our identity. And it's no surprise that HIV can have a significant impact on our experience as sexual beings—whether it's the impact of our diagnosis, which can leave us feeling “tainted” or “dirty”; the impact of the disease itself on our health, emotions and stamina; or the pressures of disclosure, condom use and

safer sex. Or perhaps it's side effects, such as lipodystrophy or diarrhea, that have taken a toll on our body, self-esteem and body image.

Sexual dysfunction in the context of HIV is understudied in both men and women, leaving many gaps in our understanding of this complex interaction. We know that sexual difficulties are fairly common in the overall population. And research indicates that issues with desire, arousal, satisfaction and orgasm—as well as erectile difficulties and problems with lubrication and pain during intercourse—are even more common in the context of HIV disease.

The causes of sexual difficulties are well documented and the impressive roster of experts interviewed for this article helps to situate them in the context of HIV: stress, anxiety, depression, body image issues, alcohol and recreational drugs (including cigarettes), as well as some prescription drugs, particularly certain antidepressants and

meds used to treat high blood pressure, cholesterol and triglycerides. Research is beginning to ask whether highly active antiretroviral therapy (HAART) is a possible cause of sexual dysfunction in people with HIV/AIDS (PHAS). HIV itself can wreak havoc with our hormones, and our hormones play an important role in regulating our libido. For instance, testosterone levels are known to be low in many HIV positive men.

Four PHAS talked to *The Positive Side* about the challenges (and, in some cases, joys!) of enjoying a healthy sex life with HIV. As they describe, it's all a bit more complicated than the cause-effect relationship that research seeks to tease out. For one, many of us had issues with sex even before we became HIV positive, so it's difficult to know how much “baggage” we brought forward into our diagnosis. Consider, for example, the number of PHAS for whom childhood sexual abuse was an issue. These

experiences affect how we construct our adult sexuality.

Secondly, when we experience sexual problems, we experience them in the context of our full and varied lives. So, it's challenging to pinpoint the source of a sexual problem. Is it depression, our meds, or the sheer exhaustion of working full-time at a demanding job that makes it so difficult to summon that loving feeling at the end of the day? Or is it all of the above? Even the most rigorous investigation of sexual problems—with a counselor, therapist, gynecologist or HIV doctor—can be challenged to come up with the cause, let alone the cure.

In the end, this article probably raises more questions than answers. While it seems likely that HIV, its associated conditions and the drugs we take to deal with these have some relationship to sexual dysfunction, it also seems likely that it will take a long time to characterize this relationship more accurately.

In the meantime, given the significance of sexual function in terms of quality of life, health care providers working with PHAs should consider incorporating questions about sexual function into their patient interactions.

And if you, as a PHA, feel unsatisfied about your sexual life, don't be ashamed to look for solutions, both creative and clinical. Talk with your sex partners and health care practitioners and check out the Internet or your local sex toy store. If you don't have someone to join you on your erotic adventure toward sexual healing, maybe this article will help you acknowledge that you're not alone and encourage you to start out on this journey and see who you meet along the way. +



Darien Taylor is the Director of Treatment Information at CATIE. She has been living with HIV for more than 15 years. Although she lamented the impact of HIV on her sex life for many years, she would now prefer to curl up in bed with a good book.



David Hoe, 62
Senior policy advisor on HIV/AIDS
Diagnosed with HIV in 1988

One of the ways I'd describe myself is somebody who has sought to have a healthy sexual identity and a sexual life that can be celebrated. I think most gay men and many PHAs have this as part of defining who we are.

How is your health?

It's the best it's ever been, and it continues to get better. (Lab work confirms the felt experience.) Part of that is by incorporating a healthy erotic self, which deeply connects to just about every aspect of life. In terms of HIV, that began upon my diagnosis in 1988 (though I think I became infected in 1984). I was the executive director of the AIDS Committee of Ottawa and one of my jobs was to create programs for PHAs. We were fortunate to have Sequoia Lundy come here and create healing workshops for us. He'd been doing healing work with gay men with HIV in San Francisco and with the emerging Body Electric School in California.

In 1989–90, Sequoia introduced clothes-off workshops of light touch for gay men in Ottawa. This began my journey of learning about my body as a temple, as a sacred part of who I am, and learning to respect my body and take care of it on multiple levels and in a holistic way.

In 1991, I got sick with PCP (*Pneumocystis pneumonia*) and went on sick leave. The few drugs that were around weren't effective enough at preventing my immune system from collapsing. I dropped down to about 10 T cells, had

We're at a point now where we can say that most PHAs are going to have long lives, and that includes sex. However, sex is a moralized aspect of life. There continues to be an attitude among some in the medical community that PHAs shouldn't have sex; for them, the idea of helping PHAs to have a good sex life is new.

Difficulty with sexual function is a common issue raised by people at our HIV clinic and I see a wide spectrum of issues and conditions. After diagnosis, some people feel that sex is the enemy because it caused them to contract HIV. They never want to have sex again. Sometimes people don't want to have sex because they're worried about infecting another person. Even many years beyond diagnosis, a deep conversation will reveal that these attitudes are often still present and preventing them from having a satisfying sex life.

Then there are PHAs who continue to have an active sex life after diagnosis but who in time lose their sex drive or sexual function. This change may be caused by the attitudes mentioned above or by HIV itself (decreases in testosterone or problems with blood circulation), HIV meds or other meds.

It's a challenge to tease out the cause. People are reluctant to change their HIV meds to see whether they're the cause of the sexual dysfunction—they're more likely to try testosterone, Viagra or Cialis. Antidepressants and beta blockers (used to treat high blood pressure) can wreak havoc on sexual function. If I suspect that's the case I try switching patients from one class to another that doesn't have these effects.

My conversations with patients about their sexual relationships are important. HIV plays a significant role in every single intimate relationship where it is present, and its impact on a relationship changes over time. As people sort through their beliefs and assumptions about their sexuality, it's great to see their eyes light up when a myth is debunked or a solution they come up with is affirmed. Through talking to me or their partners, people do discover ways to make their sexual lives satisfying.

PHAs can have great sex. You don't need to go through your life denying this part of yourself. But it can take a lot of work and it's important to talk with others—health care professionals, counselors and other PHAs who have been there. Your comfort zone will be different from that of other people, and that's all right. You need to find the sex life that's right for you.

—Dr. Dale Guenter, Family physician at North Hamilton Community Health Centre, Teacher at McMaster University

multiple episodes of PCP and major organ failure. We all silently expected that I would die, but then along came protease inhibitors and my recovery began. Six months later I returned to work, rejoining others fighting AIDS and being part of the design of the new Canadian Strategy on HIV/AIDS.

Now I'm on tenofovir (Viread), 3TC (Epivir) and Kaletra. Energy-wise, I take testosterone in the form of gel and NucleomaxX powder to remedy the damage done by many of the "d" drugs I used to take. I take a number of vitamins and other supplements to counter the toxicity of my drugs

and to keep my body as energized and healthy as possible. I use aromatherapy oils to balance my energy.

How has your sex life been since your diagnosis?

When I was sick, my libido disappeared. I was dealing with energy loss, fatigue and illness. This is part of how the body naturally redistributes its energy. I was more concerned with intimate touch of a caring kind—a stroke, being held, having company around me. When my energy started to return, so did my libido. It was a transitional moment to still be rather emaciated and sexually charged again.

When well and wanting to be sexual, I started to encounter all the shame and discrimination of being a sexual person with AIDS. So, it's necessary to come to terms with shaming and to fight discrimination and fight for the right to be sexual, but, more importantly, to develop a healthy sexual identity within that toxic environment. And that affects libido.

Also, with body shape changes—because our culture focuses on the physical form rather than the erotic form—there is work to do in regard to oneself as a sexual, attractive person. One of the things that shame, discrimination and doubt about self-attractiveness do is close down the heart centre, the place that sends out our openness or closed-ness. When we close down that part of us, our erotic energy gets trapped and doesn't become part of what people feel when we're around, so we come across as being distant and cut off.

The other thing is that the combination of HIV and meds can change the body's sexual functioning. One of the things that happened to me was the loss of ejaculation. Doctors with whom I discussed this did not know how to handle it. Ejaculation is related to energy and trust and a number of things, so that was a big identity issue for me as well.

It became very powerful for me to move into a school of the erotic arts and into a healing context where my sexual self as a person with HIV is celebrated. It was incredibly astounding to come across an environment where sexuality and erotic health is taught and cultivated and participants are challenged to explore and discover. That transformed all of those HIV experiences of sexual shame and discrimination. The school had a very good political and health-oriented approach to HIV and sexuality, which absolutely accommodated and promoted sexuality and erotic health within a framework of HIV.

Why is erotic health so important to you?

My erotic health is as important as all other aspects of my health. I view this also from a spiritual place. The spiritual aspects of erotic life lay strongly in a belief system that sexuality is holy and that the body has its own intelligence and will guide us to states of pleasure that are meant to be and that are part of creation. Few of us have grown up with this belief system.

Many PHAs have energy problems, so accessing all energy sources—including erotic energy—is important. I put a lot of attention into my breathing, especially into the

as important as all other aspects of my health.”

lower part of my body and pelvic/genital area. This is important for heightened erotic states and is interconnected with my meditation and physical exercise, which keep my body as something I respect and treasure and keep my energy moving well.

How has your sex life been affected by all this?

When I have sex with somebody now, it's much more exciting and much more conscious. It's important for me to have some kind of heart or personal connection with somebody and then to be very experimental and exploratory and to take time—to make it magnificent and sensual and to discover with somebody not in a rush what can be opened up within the body, to find out what is exciting, what is pleasurable, and to breathe. It means being able to ride the wave and to experience ecstatic forms of pleasure.

Erotic health has taken me to a redefinition of what intimacy is about. It is important to have intimacy with oneself in order to be able to share it with other people. And erotic well being does not have to be confined. For example, I have a couple of people in my life with whom I exchange erotic massages. Like many gay men, I grew up believing that the purpose of sex was to reach an ejaculation. Now I see it much more in terms of sensual and erotic energy.

Safer sex in large part has been characterized as less erotic. It's quite often characterized as DON'T. I've discovered that there are multiple possibilities of reaching intensely ecstatic states—all of which I didn't know about before and all of which are completely safe. The whole notion of “barriers” gets exchanged for “permissions,” “possibilities” and “discovery.” That's a big shift for me. It's not important to me now to have such a limited concept of what it is to be HIV, horny, excited, hot, ecstatic, safe, and sharing that with somebody. The whole notion of living with HIV and being sexually active has shifted.

Do you have any advice for people who would like to explore their erotic selves?

Unplug the phone, create a sensual place at home, get some oils, and start stroking your body and breathing attentively and noticing the sensations . . . and go with that.

There are a number of places in North America that do weekend workshops on erotic well being. Through Body Electric, people can begin the journey that I began some years ago. Within one weekend there's a transformation of awareness. It took one day for me to increase my awareness of improved meaningful erotic and sensual experience.

There are a number of books on gay spirituality including sexuality. However, few of our health resources acknowledge and work with PHAs and our sexual healing. This is a huge, shadowy silence, especially because HIV is intimately woven into our sexuality. What better people to explore sexual heights than people with HIV.

- For spiritual erotic work: *Tantra for Gay Men* by Bruce Anderson; *Desire* by Daniel Odier.
- To challenge society's way of understanding sexuality and eroticism: *Erotic Justice: A Liberating Ethic of Sexuality* by Marvin M. Ellison.

- For gay men to move toward healthier identities: *Gay Warrior* by Fickey and Grimm.
- For multiple resources on eroticism: www.bodyelectric.org
- For tender touch: *The New Sensual Massage* by Gordon Inkeles.
- For toys: Go to an erotic store or search the Internet. Follow your intuition and experiment. Treat your body and treat it well. +

Over the past 20 years I've worked with hundreds of PHAs, most of them gay men. Generally, I find that HIV tends to exacerbate whatever earlier existing emotional issues people have about sex. People's feelings about sex are deeply rooted in their emotional lives.

I find that drugs—prescription and recreational—are a big issue in terms of sexual functioning and HIV. Very little attention is paid to this connection with anti-HIV drugs because the desired treatment effect—antiviral activity—is deemed so important and consideration of side effects tends to be minimized. The correlation between HAART and sexual function is not clear to me. It's difficult to untangle all the different combinations that people are taking and say, “This drug affects sexual function this way.”

I see a lot of gay men—positive and negative, on HAART and not—who have erection problems. Loss of erection is a common problem among men, which the marketing success of Viagra attests to. Right now there is a lot of crystal meth use among gay men, and this also affects their ability to achieve an erection.

Through talking with so many gay men, I've come to understand that anal penetration and HIV are linked together on an unconscious level. Anal penetration is connected to feelings of harm, infection and humiliation of the bottom by the top. Condoms have a lot of meaning. They act as a concrete reminder of HIV and the potential lethality of the sex act. Many people also have doubts about the confidence they can place in condoms, which can tear and come off. And anal sex is perceived by gay men as a very intimate act.

Violence, humiliation, death, love, intimacy . . . this very powerful, gruesome entanglement of conscious and unconscious thoughts and feelings has an impact on gay men's sexual function.

Then there's the issue of self-esteem and its relation to sexual function. Lipodystrophy, even very subtle cases of it, can make people feel self-conscious and unattractive, and this can impact on their sexual function.

Another thing I've learned is that tops, positive or negative, often experience performance anxiety. Anxiety is anathema to an erection for physiological reasons. Anxiety has an effect on the sympathetic nervous system, causing blood vessels in the periphery, including the penis, to contract in order to better supply the central torso area with blood.

An old Gay Men's Health Crisis (GMHC) safer-sex campaign said: “Think about it; talk about it.” This applies to sexual dysfunction, too. I find that people try to muddle through on their own with these issues for too long. Talk to your partner. Talk to other gay men.

—Dr. Walt Odets, Clinical psychologist, Berkeley, California

“I think about sex and by the time I get

isn't much research on women with HIV who are my age. Why? Why can I not have sexual feelings?

You would like to?

Um hmmm! My partner is very handsome and I certainly wouldn't want to lose him to someone who's more sexual than I am. He can tell me he loves me with all his heart, but if there's no sex, the fear of him finding it somewhere else is great. That's a fear I live with every day.

I think about sex sometimes during the day—"Tonight I'm going to make a nice dinner and put candles on the table"—and by the time I get home, that thought is gone. Then the next day I'll think, "Why didn't I do that?" I can't really answer myself. I feel like I've let him down, but I also feel that I can't give him something I'm not ready to do. Besides, it wouldn't be fair to him to lie and pretend to be in the mood.

Was there a time in your life when you had a sex drive?

Yes, before I became positive. My ex-husband gave HIV to me, and his words still haunt me: "Nobody will ever touch you again." That made me feel dirty. As hard as I try to think that I'm not a dirty person, those words keep coming back.

Is there a fear of infecting your partner?

Yes, even with using condoms that fear is still there. It's not rational. That may be another reason I'm not feeling sexual.

Are condoms an issue for you?

There are condoms in our drawer all the time. When we do have intercourse, we always use a condom. But intercourse happens maybe one out of every four times that we have sex. Let's say, for instance, we had sex yesterday, which we didn't—it could be another six weeks before we have it again.

I see HIV positive women regularly for gynecological issues and I spend a lot of time talking with them about how to continue to have a healthy sex life. But I haven't seen any women with HIV who presented with a specific, primary complaint about sexual function. Usually, problems with sexual function come out as we're discussing or treating other complaints.

HIV positive women are more prone to gynecological problems than women without HIV. This is related to their degree of immunosuppression. Women with HIV are at risk for the following complications, which can affect their sex lives:

- Abnormal Pap smears and menstrual problems: Painful, irregular, heavy or missed periods can impact on a woman's sex life. It's difficult to have sex if it causes pain. And women's feelings about their sexuality can be affected negatively if they're bleeding heavily, because blood is linked in their minds to the possibility of HIV transmission.
- Other sexually transmitted infections (STIs), like gonorrhea and chlamydia, can result in a discharge, which may make women feel sexually unacceptable to their partners. Untreated STIs can result in pelvic inflammatory disease, which can cause pelvic pain if scarring results. This can make sex uncomfortable.
- Vaginal yeast and bacterial infections can create discharge, burning and itching, and, with bacterial vaginosis, a strong odour. Some women say this odour is stronger after sex, which can be a turn-off for both partners.



Liz Welkert, 50
Hairdresser
Diagnosed with HIV in 1994

My sex drive is non-existent. The thought doesn't even enter my mind. Nothing really turns me on. And it's getting progressively worse.

I've been in a relationship since 1997 and my sex drive was great for the first two years or so, but then it slowly decreased. So I went on testosterone shots, which worked for six months. But then my sex drive was down to almost nothing, so I stopped the shots because why take them if nothing's going to happen?

Now I'm off all meds as we try to figure out what I'm resistant to. I'm hoping that my sex drive will come back with my next HIV regimen. Who knows, maybe new drugs will have different side effects than the ones I was on. I just hope I don't have to go back on testosterone and start plucking hairs out of my chin.

What do you think is the cause of this problem?

There's a lot of stress. Also, I've been on so many meds and there are side effects. How can you be sexual when you're afraid you're going to have diarrhea? To some degree, mentally, I shut off that part of me.

Even though my partner is understanding, things become tense and we don't talk for a while—certainly not about the issue—and then we forget about it. I think that's part of the problem, along with the meds, side effects and stress—it's a combination of everything. It could also have to do with age. Is it menopausal? We don't know. There

sometimes during the day home, that thought is gone.”

Does your partner ever get frustrated?

Very frustrated. We'll each be at our computers, and he'll say, "Are you in the mood?" and I'll say, "Not really. Why don't you just go ahead and surf [on pornography websites]?" I think part of him can't accept the fact that it doesn't bother me.

I go to bed at night and think, "Why didn't I say yes to him?" But then I wouldn't be truthful to myself. It's taken me 50 years to be true to me, and that's hard for me to change now. I have to do what makes me feel good inside and not always worry about what makes other people feel good.

Does your partner ever feel insecure, like you're not attracted to him?

No. I don't think that's ever crossed his mind. I sometimes feel that *I'm* not attractive, because of my belly (from lipodystrophy, plus I've stopped exercising) and a huge scar on one of the cheeks on my backside from surgery. That surgery was because my ex-husband raped me, so that still plays in my mind. If I could chop off that scar, I would, just to feel a little more attractive. I hate it and it puts a damper on me feeling sexy because I know it's there. If I'm naked and I turn around, I think, "Oh, no, he's seeing the scar." And it'll never go away, so that will always be with me.

What have you done to deal with the problems related to your sex drive and to some of the issues around things that happened to you sexually?

Not really a whole lot. I wouldn't know where to go or who to turn to.

Have you talked to your doctor about any of this?

Yes. I've told him that my partner wants sex and I'm not in the mood and my partner doesn't understand why. He thinks my partner is being insensitive.

There's a significant psychological impact that accompanies an HIV diagnosis. Many women acquire HIV through sex and often tend to step back from having sex after they're diagnosed. There are fears about disclosure and rejection.

Although it's difficult to tease out the impact of HIV meds, I feel that some side effects change women's sexual function—lipodystrophy causes changes in the breasts and abdomen and can really affect one's body image. Although I can't find a clear correlation between HIV meds and changes in sex drive, side effects like nausea and diarrhea certainly make people not want to have sex. Also, some antidepressants cause changes in sex drive, and there is a lot of depression in women with HIV.

We don't know a lot about menopause in HIV positive women and its effect on sexual function. Women are only now living with HIV long enough to go into menopause, and we're only recently beginning to see more HIV diagnosed in older women. Menopause is a time of changes in libido, mood and sleep patterns and can cause vaginal dryness, which can all impact sexual function.

It's very important for HIV positive women to have an annual exam with a Pap smear. Women with HIV who have issues related to their sexual function should not hesitate to ask their doctor for a referral to a gynecologist, preferably one who knows about HIV.

—Dr. Mark Yudin, Obstetrics, Gynecology and Reproductive Infectious Diseases, St. Michael's Hospital, Toronto

I've worked with a number of PHAs in my practice and, interestingly, HIV itself has never been at the root of their problems.

People often think that their problems will be "cured" by seeing a sex therapist. But a cure isn't always possible. What I can do is help an HIV positive person with sexual dysfunction come to terms with and do the best possible job of managing the reality of their health situation and its impact on their sex life and relationships.

Before we meet, I have my clients do some preparatory homework. I ask them to outline their problem and what would need to happen in order for them to view it as resolved. Depending on their answers, I can provide them with current information about drug therapies and interactions or I can engage them in a discussion about their attitudes to sexuality and relationships.

If you're experiencing sexual dysfunction, you don't need to feel alone and ashamed. Talking about your problems with an objective, informed and empathic therapist can be transformative. My website (www.smartsextalk.com) is a useful resource for PHAs who have issues with sexuality and sexual function.

—Dr. Pega Ren, Sex therapist, Vancouver

Have you thought about seeing a sex therapist, either with or without your partner?

I don't know if I want to go to a sex therapist. I was sexually abused as a child for 10 years, and I don't want to go back to those memories. It's not easy to talk to someone I don't know, particularly a man. I'm afraid of exposing myself and these parts of my life to someone else. I'm afraid of being judged. I'm afraid that memories and feelings might come out in the course of therapy that would ruin my relationship with my partner.

I don't want to draw my partner into the conversation for fear of embarrassing him. It's my issue. I know because he's my partner it's also his issue, but we've never really discussed it. All I can say to him is, "Honey, I don't understand it. I can't explain why I'm feeling this way." And I really can't.

Have you ever watched porn together or used sex toys or tried anything like that?

Yes, everything. Seeing pornographic pictures on the computer helps me fantasize but it doesn't make me want to have sex with my partner.

Is there a part of him that's afraid because you have HIV?

Yes. I know he's afraid. We've tried Saran Wrap, we've cut the condom in half, but I think there's such a fear of becoming infected that he's not letting himself enjoy that part.

I don't know if I'm in a rut, I don't know if this is part of what we HIV positive women go through. I'm hoping to hear from other people that I'm not the only one having these problems. I feel like I am the only one because I have no one to talk to about it. I wish I had a girlfriend I could sit down with and say, "I just can't. Is there anything wrong with me?" +



Stephen Frey, 42
Unemployed
Diagnosed with HIV in 1992

I'm single. I've dated and been in relationships, but nothing really long term. I'm not the kind of person who goes looking for a boyfriend. If it happens, it happens. I'm not too hung up on it. I find it difficult when I start dating somebody because sometimes I just don't feel very sexual.

A few years ago I met somebody in Germany. I liked him very much and we got along very well. He visited me a couple weeks later. When he was here, I wasn't getting horny. I wasn't able to get an erection. I think with gay men sometimes if sex isn't pretty good fairly soon they lose interest. I just wasn't feeling sexual and I wasn't able to perform, and he lost interest pretty quickly. I regret that because he was quite special.

It made me very insecure. I suppose the tendency would be to go for anonymous situations where there's no chance of bonding in that kind of way, which isn't really what I want. So I went to my doctor. This was before sexual function problems were discussed very often in the medical community with HIV positive people. I was embarrassed bringing up this problem with my doctor. I assume a lot of men are. When it comes to self-image maybe we put too much emphasis on our erections. I told my doctor: "I'm 38. I'm with somebody I get along with, I've been honest with and I'm attracted to, and it's just not happening for me. That's not normal." My doctor agreed. He prescribed testosterone patches, which helped make a difference—there was a subtle improvement and no side effects.

I smoke cigarettes, which doesn't help the situation. I was also having anxiety problems, and my inability to perform seemed to do with that as well. I tend to be kind of a nervous person. I've worked rather hard to be more comfortable with myself, but I have other issues outside of HIV and sex.

Can we talk about that? Because it's not like life begins or ends with HIV—we carry who we are into our diagnosis. So, tell me about that person that you are.

I always had sexual hang-ups. I started becoming sexually active in the early '80s. I had a very romanticized view of how things would be and I ended up with guys who would cheat on me or lie to me, which was devastating. It made having relationships a lot more difficult, because here were people who supposedly cared for me who didn't treat me very well. I had trouble standing up for myself and I carried that for a long time. So I think my nervousness was already there, and HIV exacerbated it. One good thing that came out of being HIV positive is that I work very hard at being more open and addressing these things.

Has HIV had a negative impact on your sex life?

After my diagnosis, it was almost like I became hypersexual but without necessarily acting on it. I just wasn't able to function in the same way. It was very weird. My sex drive increased but my ability to get an erection decreased. I was nervous about sex as it was anyway, so then having trouble with sexual function and getting an erection just made me more nervous and less open.

So would you say your major sexual issue is your inability to get an erection?

I'd say the issues are both physical (erection problems, loss of libido) and psychological (anxiety about erection problems, fear of passing on the virus, negative self-esteem due to body shape changes). I'm part of an online group for gay positive men called gaypoz.org. Other positive men I've chatted with online have told me that they have similar issues concerning sex.

Working at BCPWA, I've noticed that a large percentage of the people who come in for consultations have at some point experienced sexual dysfunction—from decreased libido to vaginal dryness to erectile dysfunction. The sexual challenges are often accompanied by a profound sense of inadequacy or shame.

Unfortunately, many people don't know that sexual side effects are common and are often due to meds or stress. Shining the light of knowledge and acceptance on the issue is the first step toward minimizing negative associations. There is strength in dispelling the stigma of sexual issues, and only by voicing your concerns can you begin to get the help you need.

I treat sexual dysfunction as part of the bigger picture. Through understanding what imbalances exist in terms of nutrition, energy, lifestyle, metabolism and stress, treatment programs can be developed to treat the whole person and alleviate the associated symptoms. Using varying combinations of acupuncture, homeopathy, nutritional supplementation, botanical extracts and counseling can help with overall health and, by extension, sexual dysfunction. Alternative medicine can provide relief and support for those suffering with sexual challenges and, as an added bonus, improve the general health and quality of life of PHAS.

—Dr. Jennifer Hillier, Naturopathic doctor, Vancouver

I've been working with PHAs for 13 years. Sometimes patients are referred to me specifically because of sexual dysfunction and sometimes this concern comes up in the course of therapy for other issues.

I try to ensure that, first of all, my patients have a thorough physical assessment with a physician to rule out medical conditions that can impair sexual function (such as diabetes, heart disease, fluctuating hormone levels). A physical checkup is very important because people often make assumptions about what is causing their sexual problem, and a checkup can identify a condition that the person may not have been aware of.

If the patient is cleared medically, I work with them to identify possible psychological reasons for their problems. These may be behavioural, cognitive or emotional and may include such things as: substance abuse, unresolved grief and loss, concerns about HIV transmission, and body image issues, especially if the person has lipodystrophy.

Some of the issues are directly HIV-related and some are not. Depression and anxiety can cause a lack of sexual interest. Discomfort with one's sexual orientation can result in shame, which impairs a person's sexual performance. Issues that may have been present prior to the person's HIV diagnosis relating to trust and fidelity or past sexual trauma can play a role. Meds to help stabilize

a person's mood can cause sexual dysfunction, and there is the need to carefully balance mood stability and sexual function.

Depending on the factors involved, I will work with the person or couple to tailor a course of treatment to suit their needs. This may include couples therapy, treatment for anxiety and/or depression, substance abuse treatment, correcting misinformation or dysfunctional thinking, and/or working on self-esteem.

As a clinical psychologist, I don't prescribe meds, but I can encourage patients to discuss prescriptions with their physician and I also provide education on how to talk with their physician about these issues.

I hear from some of my patients that the health care professionals they've been dealing with haven't taken their complaints about sexual function seriously. If the patient is gay, homophobia may be behind this. Or health care professionals may be accustomed to thinking of HIV as an issue of survival first and foremost rather than considering quality-of-life issues. Keep at it until you find someone who takes your issues seriously.

—Dr. Jennifer Hendrick, Clinical psychologist, Queen Elizabeth II Health Sciences Centre HIV Clinic, Halifax

“I found it easier to get an erection off meds.”

What have you done to address the physical problem, besides taking testosterone?

A couple of years after using the testosterone patch, my doctor took me off it because my levels were high and it seemed to add to my anxiety. My GP sent me to a urologist. I was the only person under 50 in the room. The urologist prescribed Viagra, which didn't work that well for me. Now I take Cialis from time to time, which I find works better than Viagra.

Have you tried any complementary therapies?

Ginkgo is supposed to help blood circulation and help with erections. I tried it, but it didn't seem to make much of a difference. Maybe I didn't use it enough. I kept reading about possible interactions between herbs and HIV meds, and I decided to stay away.

What about the smoking? Did any of the doctors say that could be implicated?

Definitely. I smoke about half a pack a day. I'm trying to quit. It's very difficult. It's always in the back of my head that I should quit for a whole bunch of reasons but I haven't yet.

And how have you dealt with the psychological issues?

I saw a psychologist and I joined group therapy. The focus of the group therapy was intimacy, and it helped but it was a slow process. I was also seeing a psychiatrist periodically to adjust my antidepressants.

Antidepressants can also have an effect on sexual function.

The one I'm on now, Wellbutrin, doesn't. I would say it helps sexual function more than anything. I was on Celexa first, and that made it almost impossible to reach orgasm.

How is your overall health?

Not bad. I've been on quite a few combinations. Now I'm on Sustiva (efavirenz), Viread (tenofovir) and Videx (ddI). I'm

taking part in SMART, a study about structured treatment interruptions. I stopped meds in May, but my numbers declined rather quickly so I had to go back on in July.

I felt good being off meds. I sort of felt more like me. To be perfectly honest, I found it a lot easier to get an erection off meds. Was it psychological? I don't know. But I've noticed a change since I've been back on meds, and I don't think it's just in my head.

How do condoms fit into this for you? Many men find that condoms inhibit their erections.

Yeah, putting a condom on can basically kill it. That's why I think a lot of positive men choose not to use them. That said, I do find condom usage to be fairly high in Halifax and I use them myself.

What's the situation with your sex life now?

I'm not looking for a boyfriend at the moment. I have sexual partners from time to time. For the last three years that I was living in Montreal, I didn't have sex much at all. I was avoiding it. When I moved to Halifax, my doctor asked about my sexual activity, and my reply was “not very often.” He said, “Oh, that'll change. You're in Halifax.”

In many ways, things are better for me here. I do have more sex here. There seems to be a lot of sex going on in this town. And I'm more comfortable with myself. A lot of guys are chatting online. I've done that a few times but I haven't actually met anyone “in the flesh” this way. I prefer meeting people one on one. Exchanging pictures doesn't do it for me. A picture doesn't show all of somebody's attractiveness, so I don't put a lot of stock into that.

I'm still basically a romantic at heart. I think a lot of gay men have trouble combining sex and intimacy, and I've been one of them. I'm hopeful I'll get it right one of these days. +

“I have a problem with the

What’s right for me isn’t necessarily going to be right for someone else.

How did this all affect your sex life?

Sometimes we wouldn’t have sex or we’d stop because I felt like she wasn’t comfortable doing certain things. That was hurtful sometimes, especially in the beginning of my diagnosis because I felt kind of poisonous around sex and being touched, almost like I didn’t have a right to be sexual. Some of it was me projecting my feelings about myself onto her and feeling shitty about my body and sexuality. And she didn’t want to hurt me by saying she was uncomfortable.

Now my partner and I check in with each other from time to time. I’ve had to say to her, “I feel like we don’t ever talk about HIV and that’s weird for me because it’s such a big part of my life.” I live with HIV and work in the community, and yet I don’t talk about it with her very much. So I make sure we do. I’ll bring home an article for her to read or I’ll try to bring up how I’m feeling about stuff. If there’s tension around sex, we try to talk about it.

How did you deal with coming out and finding out you had HIV at the same time?

When you’re first coming out, under usual circumstances it can be a chance to explore different people and try different things sexually. Being diagnosed with HIV inhibited that in a lot of ways because I was scared of infecting other people and of how people would react. I felt that I couldn’t have sex without disclosing because there’s so much guilt around it, whether or not you use protection. I told my partner I have HIV on our second date because I wanted to get the rejection over with.

Ever since coming out, my sex life has gotten better. Sex with women made that happen as well. I feel comfortable being a dyke and being with a woman and feeling solid in my relationship. Also, that stuff around early diagnosis and feeling poisonous and ashamed about my body has for the most part dissipated, which has made sex a lot better.

Where did you access support and safer-sex info?

There isn’t a lot of support in the lesbian community

For the past 10 years, my work has focused on sexual health, especially on viral STIs like HIV and herpes. Therapy work with PHAs includes accompanying them through different stages, in life and with regards to HIV, and helping them manage their disease at the psychological, relational and sexual level.

In my practice, I notice that the psychosexual aspect of HIV tends to affect self-esteem when it comes to body image and feeling desirable. There is also an increased fear of being abandoned. Loneliness, fear of disclosure and rejection, personal anxieties and physical impacts of HIV are other factors that can affect the sexual lives of PHAs.

Despite some limitations or changes we have to make to our sexual health, it is possible to enjoy a fulfilling and responsible sexual life. All we have to do is take the time and use the necessary resources to progress toward accepting and adapting to HIV. Some resources for PHAs include: help and information lines on HIV/AIDS and other STIs, community organizations, personal growth activities and groups, and professional therapeutic care by a sexologist or a psychologist specialising in HIV.

—Katia Sénéchal, Clinical sexologist and psychotherapist, Project Officer for the HIV/AIDS, Herpes and STI phone line at CRISS, Montreal



Danielle Layman-Pleet, 28
Peer Network Coordinator
Diagnosed with HIV in 2001

I identify as queer. I used to have relationships with men, but I came out around the same time I was diagnosed with HIV. It was interesting to deal with those two things at the same time.

Are you in a relationship now?

I’ve been with my partner for about four years. We got married about a year ago. We have our ups and downs like every relationship, but it’s a good relationship.

HIV has been something we’ve had to negotiate around in our sex life and our emotional life. Initially, I had to go through a waiting period for her to decide, it felt like, whether I was worth it, in relation to me having HIV. Would the HIV win or would my personality win? HIV isn’t something she was used to having to deal with. Lesbians don’t tend to see HIV as part of their reality. It’s not something they often talk about.

Not only was I having my first serious relationship with a woman but I had to negotiate sex and figure out what’s safe and what’s not. Because there’s such a lack of information around safer sex for women who are with women, my partner had a lot of fears around transmission that sometimes weren’t realistic. So I had to find the information and reassure her, but I didn’t have anything to back up what I actually thought was realistic in terms of transmission. For instance, there isn’t much information around oral sex for women. We hear it’s low risk, but it’s a confusing space to be in when you’re negotiating around that stuff.

I told my partner I didn’t want to be the only one providing her with this information. She needed to do her own research and talk to other people. I didn’t want her to feel that I had some kind of agenda. I think the onus is often on the positive person to be the educator. But, at the same time, people need to find out for themselves because each of us is comfortable with different levels of protection.

phrase sexual dysfunction.”

around HIV. Women with HIV are pretty invisible in a lot of ways. As I started to tell some of my queer friends, I realized they didn't know much about HIV.

On the flip side, a lot of the workshops on safer sex don't focus on woman-to-woman transmission or sex. In HIV support groups, at first I didn't feel comfortable talking about being a dyke because I wasn't sure how it would be perceived by other women with HIV.

So I didn't have much support. But four years later, I've found a handful of other lesbian and bisexual women with HIV. It's great to have social relationships with them and have a bit of a community. Having the peer support—hanging out, joking and laughing about sex, and celebrating the fact that we are sexual and have sex lives even though it's complicated—has been so important for me. I think it's great to celebrate sexuality when you're a positive woman because it's something that's not acknowledged a lot. Also, Voices of Positive Women, where I work, is a queer-positive space.

How is your health?

Really good. I haven't had any health scares yet. I've decided to try to stay off meds for as long as I can; I've never taken them. My CD4 count has stayed pretty stable around 350. I'm doing some alternative therapies: I see a naturopath and do acupuncture, take supplements when I remember, and try to get lots of exercise.

Have you had any health problems that affect your sex life?

I don't feel very sexy when I have a yeast infection. Sometimes sex can kind of irritate that stuff and make it happen more frequently. We've had to figure out how to be creative—sex toys are definitely a fun way to have safe sex. When I get a yeast infection, I use this stuff from my naturopath called Megadophilus (a really strong dose of acidophilus in a vaginal and oral capsule) that clears it up. I try to avoid sugar and alcohol when I feel something coming on. Yogurt's good. I'm all about the natural remedies these days.

Do you have any final thoughts on sexual dysfunction in the context of HIV?

I have a problem with the phrase *sexual dysfunction*. We all have different experiences that contribute to the way we feel about our bodies and sexual identities. Some of us have been raped or been through sexual abuse or have come out—all kinds of things. An HIV diagnosis can be part of that as well, and I find the whole idea of labeling these things as “dysfunction” kind of problematic.

Of course these experiences are going to affect the way you experience sex and express yourself, and I think that's sexually a really normal response. To be pathologized isn't helpful. Immediately I think of those kinds of sexual diagnoses and my mind jumps to “medicate.” I don't think that's always the answer for people. It makes you feel like you're a freak for feeling a certain way or responding in a certain way to stuff that's happened in your life.

I think sex can be a really powerful place for people to heal some of that stuff and to connect with other people and feel good about their body. Everybody deserves to have a

Living with HIV can mean more stress as well as a variety of meds that can cause sexual dysfunction. Some types of sexual dysfunction can be directly linked to certain meds—lowered libido is a common complaint for people taking antidepressants—and can be treated by adjusting the dosage. (Always talk to your doctor before changing, reducing or stopping any kind of medication.) Other times, it may be harder to pinpoint the cause of sexual dysfunction.

If your sexual responses have changed for any reason, discuss it with your doctor. Some doctors may say this isn't important if you don't have a partner or they may question your right to sexual activity. Don't settle for this! Your sexuality is a valid and vital part of your identity.

Men may experience erectile dysfunction as a consequence of certain meds. Don't hesitate to discuss this with your doctor but keep in mind that there are non-drug options—for example, many penis pumps are FDA-approved to help by drawing blood flow and achieving an erection, which can be maintained with a firm cock ring around the base of the penis.

Women may experience vaginal dryness due to stress, medication changes or hormonal fluctuations. This can be fixed with lubrication, but be sure to read the ingredient list. Use water-based lube without sugar, as sugar can cause yeast infections. Astroglyde, Probe and water-based lubes sold in drugstores are good choices. Avoid oil-based lubes, which not only destroy condoms and latex toys but can also trigger vaginal infections. If you're prone to yeast infections, find a lube that does not contain glycerine. Hathor Aphrodisia is a Canadian-made glycerine-free lube.

Another common problem, particularly in women, is difficulty achieving orgasm. Your orgasmic response may be slower and may require more powerful stimulation than before. Adult toys can help with new and different stimulation. Clitoral vibration is a popular choice for easier and more intense orgasms. The Hitachi Magic Wand is a high-quality, powerful vibrator often recommended by sex therapists as a clitoral stimulator for women who have difficulty reaching orgasm. There are also many small, inexpensive and effective hard plastic bullets designed for this type of stimulation.

Anal stimulation is another option for men and women. The anal region is rich with nerves, and gentle stimulation in this area can add a new level of sensation, particularly when in conjunction with clitoral or penile stimulation.

A note of caution: Adult toys are classified as novelties, not health items, so they are not subject to rigorous testing and standards. Many common and inexpensive toys are made of jelly rubber and soft vinyls, which are porous, meaning they can emit substances such as phthalates (a plastic-softening agent linked to health problems in some studies). They can also absorb and harbour bacteria and yeast and often cause general skin irritation in people with sensitive skin. However, these porous toys are far cheaper than their higher-quality counterparts. If they're your only option, be sure to use them with condoms. I highly recommend the top-quality medical-grade silicone toys if you can afford them—they last longer, are a better investment and can be cleaned with antibacterial soap and water.

If you are shy about purchasing adult toys at a local store or unable to find a good store in your area, you may want to consider buying online. Ticked Pink Toys (www.tickledpinktoys.com) is a Canadian e-store with a good selection of quality toys at competitive prices.

—Jennifer De Roo, Founder of Ticked Pink Toys Ltd., Vancouver

good, healthy sex life, and that's their choice, too. Love your body, if you can. Sex is an important part of all of our lives, and it's important to make sure you have an outlet to express what makes you feel good and not just what makes your partner feel good. +



Resistance



The ins and outs of HIV drug resistance testing

BY CAROL MAJOR

The trouble with HIV is that it's so stupid . . . it's smart! Owing to its own "design flaws," the virus sometimes manages to outwit the drugs used to keep it under control. This has led researchers to develop sophisticated scientific methods for analyzing *drug resistance*, helping us to keep up with some of the treatment challenges that HIV can throw our way.

The HIV virus is a mindless little robot, programmed to do just one thing: make millions more copies of itself. Antiretrovirals, the drugs that fight HIV infection, are designed to interfere with this *replication* process and prevent the tide of new virus from being formed.

If HIV always made perfect new copies of itself, these drugs would actually have a much easier job. An antiretroviral drug would face the exact same task every time, so if one were effective, it would always be effective. Unfortunately, nature doesn't work that way: HIV, being a little bit "stupid," makes mistakes every time it builds a new virus. These mistakes, or *mutations*, lead to slight differences in every new virus. Sometimes these new, mutated viruses can resist the drugs that should be controlling them . . . making it difficult to find a drug combination that keeps working.

Resistance testing is a way of finding out which drugs are still likely to be effective against mutated strains of virus—and which ones will *not* work. Resistance testing is a rather complicated business, even for experts. Your

inner science geek may be curious about how it works—it's actually quite the story. More pragmatically, you should know *when* it's important to have testing done and *what* the results can (and can't) tell you.

HIV'S GENE MACHINE

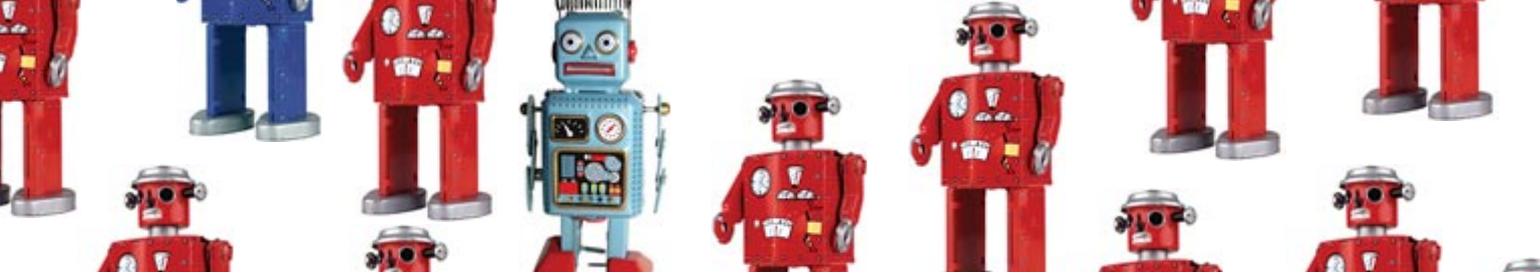
Like every living thing on earth, HIV is based on genetics. HIV's genes—long string-shaped molecules—spell out the entire instruction book for building new viruses.

HIV has a natural tendency to mutate. That means that its genes and therefore the virus itself are slowly but constantly changing. Genetic changes lead to mutations—corresponding changes in the virus' structure, shape and response to drugs.

By studying these mutations, investigators can potentially map different subtypes of HIV in different regions of the world and determine whether one particular person may have infected another. However, the most important use of HIV genetics is identifying drug resistance.

WHERE DOES DRUG RESISTANCE COME FROM?

Mutations of some sort are produced every time the virus replicates. This usually happens more or less at random—purely as a result of mistakes in the replication process. Many of the resulting mutations don't make much of a difference:



Assistance



- **Silent mutations** change the genetic makeup slightly but do not physically change the virus in any detectable way.
- **Polymorphisms** change the physical makeup of the virus but do not necessarily cause drug resistance. In fact, some of these polymorphisms actually harm the virus: These “crippled” variants can’t survive or reproduce as well, so they tend to die out quickly. Others are fairly neutral—the new virus is different but not in any significant way. (Similarly, human genetic differences result in different eye or hair colour, or whether or not you can curl your tongue.)

Even with these mutations, some viral strains—called *wild-type*—tend to predominate. Despite the name, these “wild types” aren’t microscopic party monsters; they’re just the “naturally occurring” forms of HIV—the strains that tend to persist in people who are *not* taking anti-HIV medications.

Then there are other, nastier forms of mutations:

- Some mutations cause drug resistance by physically changing the

virus so that it is no longer sensitive to one or more drugs. (*Drug sensitivity* is a measure of how well a drug suppresses, or controls, the virus.) Some of these are classified as **primary mutations**—the “prime suspects” that severely limit a drug’s effectiveness.

- Any mutation that doesn’t completely cripple the virus will be passed on to its “offspring,” which can then accumulate more. Therefore, after a few generations, a single virus may have many mutations. Some of these so-called **secondary mutations**

do not cause drug resistance on their own but do contribute *en masse* if enough specific ones pile up.

- Some mutations do not affect the amount of drug resistance a virus has but, instead, help a virus with resistance mutations to grow more quickly. These are called **compensatory mutations**.
- Finally, some mutations actually *reverse* the effects of others, so that a virus with a resistance mutation may become somewhat or completely sensitive to that drug again. These are called **antagonistic mutations**.

RETRO SCIENCE: DNA, RNA AND ALL THAT JAZZ

HIV is from the family of retroviruses. Although these days being “retro” is akin to being cool, in the case of HIV it literally means *backwards*. Whereas the HIV virus’ genetic material is **RNA** (ribonucleic acid), most of the rest of nature mainly uses **DNA** (deoxyribonucleic acid) as genetic material. RNA is used primarily for the grunt work—sending messages, shunting building blocks back and forth, and other construction activities.

HIV, being retro, takes the unusual step of using RNA for its genetic material. It then has to work backwards, making DNA from its RNA before it can actually reproduce itself. This requires an enzyme called *reverse transcriptase*.

Reverse transcriptase doesn’t do this very well at all. Rather than creating exact replicas of new DNA, it continually makes mistakes. This is where mutant viruses come from.

HOW DO MUTATIONS PRODUCE DRUG RESISTANCE?

HIV needs to produce an assortment of proteins, like a viral “toolkit,” in order to do its job. Antiretroviral drugs generally work by a lock-and-key effect that prevents one or more of these proteins from doing its job. However, if a viral protein physically changes in just the right way, that mutation may allow the virus to escape from the drug’s “locking” effect. Drug-resistant mutations cause these specific changes to viral proteins—changes that usually weaken the virus slightly but allow it to evade the drugs.

HIV doesn’t necessarily want to mutate into a drug-resistant form. However, when the virus is not completely suppressed, billions of new and different viruses are continually being produced. It can be just a matter of time before the virus stumbles on a mutation that gives it some resistance to a particular drug. (Picture an obsessed locksmith making keys at random. Sooner or later, one may fit the right lock.) If you aren’t on meds, drug-resistant viruses may appear by chance, but they don’t have any particular advantage. In fact, they are usually weaker than their unmutated relatives and don’t reproduce fast enough to survive very long.

However, if you are on meds, the viruses are swimming in a sea of antiretroviral drugs that are trying to stop them from replicating. If one little virus has a mutation that allows it to replicate easily in the presence of those drugs, even while all its relatives remain suppressed, the resistant virus will “preferentially” replicate until it becomes the main virus in the mix.

Also, since drugs within each class are structurally similar, resistance to one may mean resistance to others in its class as well—a scenario known as *cross-resistance*.

BUT I TAKE ALL MY MEDS— WHY DO I HAVE RESISTANT VIRUS?

Resistance mutations are most likely to arise in the presence of less-than-effective drug concentrations in the blood. Scientists have shown that patients taking some but not all of their meds have the fastest development of mutations. That’s why there is so much emphasis on *adherence*. It is important to try to have *all* of your drugs in your system at *all* times to keep resistance from emerging. Most importantly, do not take only one or two drugs of your combination.

Low drug concentrations can also occur in people who are fully adherent to their medication, due to factors such as poor absorption, rapid drug clearance and drug interactions.



If a viral protein physically changes in just the right way, that mutation may allow the virus to escape from a drug’s “locking” effect.

Therapeutic drug monitoring, which measures drug concentrations in the blood, might be helpful for identifying these problems, but it is generally not available. Drug interactions, however, can be avoided with careful prescribing.

DETECTING DRUG RESISTANCE

There are two main methods for detecting drug resistance: **phenotyping** and **genotyping**.

The seemingly most direct way is to try to grow the virus in a test-tube in the presence of measured amounts of drug. If it grows, it is resistant to the drug; if it does not grow, it is sensitive. This is called *phenotyping*. Phenotyping measures just *how* sensitive or resistant a virus is—whether it grows quickly, slowly, or not at all. Though phenotyping seems like the most straightforward method, it is technically quite difficult to do and is

rarely used in practice. Phenotyping is not routinely done in any labs in Canada, although Dr. Mark Wainberg has recently arranged a pilot project in Quebec, sending specimens to the Virologic laboratory in California.

An alternative method, called *genotyping*, is by far the most common method of assessing HIV drug resistance. Although the process seems (and is) very complicated, it boils down to a job of translation—somewhat like reading Egyptian hieroglyphics or computer code. At the resistance testing labs, technicians take a “viral fingerprint” (the genetic structure of the virus) and turn it into tangible information: how well various drugs can control HIV. When we look for mutations, we are comparing the individual viral fingerprint to the normal wild-type virus. Any differences from wild-type represent spots where the virus has mutated.

The final, crucial step in genotyping is to assess whether these mutations represent drug resistance. There are three major commercial genotyping technologies that do this in different ways:

- **vircoTYPE** uses a “virtual phenotype.” This is a large and growing “library” that matches up known mutations with known degrees of resistance to various drugs.
- **Bayer TRUGENE** uses an expert panel to assess and identify the specific drug resistance mutations.
- **ViroSeq** matches resistance mutations to a standard database to determine the potential for drug resistance.

Though all three technologies provide similar results, there are important differences. For example, the virtual phenotype gives an estimate of the degree of resistance caused by a given set of mutations, while the other

approaches only state whether you are resistant or not. In addition, sometimes the approaches used to interpret the mutation data can result in entirely different results for the same sample.

Genotyping for assessing HIV drug resistance is widely available in Canada. Different provinces have different guidelines and use different kits or methods, but usually physicians can order the test by indicating a viral load rebound or failure to respond to therapy. Genotyping immediately after seroconversion can be more problematic but can usually be arranged. It is also becoming increasingly important to have phenotyping availability to sort out treatment options for those with complex drug resistance patterns.

WHAT DOES GENOTYPING TELL YOU?

Resistance test reports generally provide a detailed list of all of the specific mutations found in the viral population tested, plus a summary of the corresponding levels of drug resistance. The summary often uses colour codes to flag varying degrees of drug resistance. The detailed mutation data allow physicians to combine their own expertise with the summary and interpretations of the report.

Certain cautions have to be observed when interpreting a genotypic test result. These include the following:

- Viral load must be more than 250 copies/ml for the test to be successful.
- When assessing treatment failure, patients should be actively taking medication for the test results to be accurate. Mutations cannot be detected during treatment interruptions even though they may still be around.
- Mixtures of mutations (more than one mutation at the same “site”) sometimes may not be detected by the test if they are present in small amounts.
- Cumulative records of drug resistance tests should be reviewed when making treatment decisions.

Drug resistance testing is just one of many factors to be considered when making treatment decisions—along with your treatment history and your own judgment as to how you can handle side effects and the demands of drug adherence.

WHEN TO TEST

There are two points in time when it is useful to do drug resistance testing.

1. Drug resistance test results are particularly important if and when *drug therapy fails*. If you’ve been on therapy for some time and your viral load begins to “break through” (rise again), a prompt resistance test can identify which mutations have occurred. This information is invaluable for choosing a successful next regimen before more mutations accumulate and further complicate the picture.
2. A test should be done *as soon as possible after diagnosis*. If you are infected with an already-resistant strain of HIV but are not actively taking meds, the mutated HIV strain will diminish until it is not detectable by resistance tests. The transmitted mutations are still stored in your body, even though they may seem to disappear as the majority of the virus naturally “reverts” to wild-type. A resistance test done later might not pick up these mutations and may not provide an accurate picture of all the drugs you could be resistant to.

Dr. Paul Sax of Boston, Massachusetts, recently published a paper showing that resistance testing at initial HIV diagnosis—before treatment is started—can guide a doctor to select the appropriate treatment regimen and improve a patient’s outcomes. In Canada, between 7% and 15% of those just diagnosed have HIV resistance mutations. So, even if you have no intention of starting therapy soon, a resistance test done as soon as possible after infection provides valuable information for future medication decisions. A more cost-effective approach might be to store the sample and do the test when you decide to start treatment.

BASIC STEPS OF GENOTYPING

- 1 Pick apart the viral genes to isolate the ones that deal with how the virus reacts to drugs.
- 2 “Amplify” these genes to make sure there is enough for the test to work on.
- 3 Lay out the exact chemical structure of the genes in a process known as *genetic sequencing*.
- 4 Analyze this chemical sequence, or genetic “fingerprint,” to determine how much the virus is resistant to various drugs.

All genes—whether they’re yours, a housefly’s or HIV’s—are made of long strings of just four smaller molecules (“nucleotides”) repeated in a very precise coded order. Think of a long string of beads—black, white, red and blue. That long sequence of coloured beads contains all the information needed to build a new virus.

Mutations are places where the “normal” colour has been replaced by a different one—a blue bead, say, where a red one should be. (In fact, the “coloured beads” are called *nucleic acids*, and we represent them with the codes A, T, C and G. So a string of normal viral DNA might be spelled “ATCG,” and a mutated variation might be “ATTG.” Computers are perfectly suited to scan the seemingly endless strings of letters for differences—a task no human would want to tackle.)

ACTING ON RESULTS

Doctors and PHAs face many challenges in balancing the results of these tests with quality of life and other factors. For instance, there is still somewhat of a dilemma in deciding how to handle an otherwise-healthy PHA who has a low but detectable viral load (say, in the low thousands) on a well-tolerated regimen. Sometimes the push to undetectable has very undesirable effects related to tolerance and toxicity. On the other hand, switching may preserve the usefulness of the other drugs in the regimen. With pros and cons on both sides, this is a decision to be made carefully by the doctor and patient.

READING RESISTANCE

DRUG TRADE NAME	GENERIC NAME	FOLD CHANGE	CUT-OFF	RESISTANCE ANALYSIS
Nucleoside and Nucleotide Reverse Transcriptase Inhibitors (NRTI, NtRTIs)				
Mutations: 20wt/R, 67G, 70wt/R, 184V, 11K, 228H				
Agenerase®	abacavir	1.5	2.0	SUSCEPTIBLE
Videx®	didanosine	1.2	1.3 - 3.0	MAXIMAL RESPONSE
Emtriva®	emtricitabine	48.8	3.7	RESISTANT
Epivir®	lamivudine	47.9	1.1 - 3.7	MINIMAL RESPONSE
Zerit®	stavudine	0.7	1.1 - 2.2	MAXIMAL RESPONSE
Viread®	tenofovir	1.4	1.0 - 2.0	REDUCED RESPONSE
Hivid®	zalcitabine	1.4	3.0	SUSCEPTIBLE
Retrovir®	zidovudine	1.2	1.9 - 4.4	MAXIMAL RESPONSE
Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)				
Mutations: None				
Rescriptor®		1.6	7.7	SUSCEPTIBLE
Sustiva®		1.0	3.4	SUSCEPTIBLE
Viramune®		1.3	5.2	SUSCEPTIBLE
Protease Inhibitors (PIs)				
Mutations: 10V, 13V, 22V, 33I, 35D, 36I, 46I, 54V, 60E, 82A, 83D, 89I				
Agenerase®	amprenavir			MINIMAL RESPONSE
Agenerase® - boosted	amprenavir			REDUCED RESPONSE
Reyataz®	atazanavir			RESISTANT
Lexiva®, Telzir®	fosamprenavir			RESISTANT
Crixivan®	indinavir			MINIMAL RESPONSE
Crixivan® - boosted	indinavir			MINIMAL RESPONSE
Kaletra®	lopinavir/r	11.8	10.0 - 61.6	REDUCED RESPONSE
Viracept®	nelfinavir	29.7	1.0 - 1.5	MINIMAL RESPONSE
Invirase®, Fortovase®	saquinavir	4.7	0.7 - 1.0	MINIMAL RESPONSE
Invirase®, Fortovase® - boosted	saquinavir/r	4.7	1.1 - 12.0	REDUCED RESPONSE
Aptivus®	tipranavir	1.6	1.6	SUSCEPTIBLE

Mutations are the exact locations on the HIV gene that have changed from "wild-type."

Amount of resistance / loss of drug effectiveness (higher numbers = higher resistance = less effective drug)

This is the bottom line: how effective the drug will be. (Maximal = most effective; Susceptible = good; Reduced response = less effective; Resistant or Minimal = not effective)

One of the newest directions in resistance testing is the concept of the "virtual virus." Once a mutation occurs, it is "archived" in your blood cells. It may then be "overgrown" by other viral strains, so that subsequent resistance tests may very well miss it. However, the archived mutation remains ready to re-emerge if the drug that caused it appears on the scene again.

For this reason, Dr. Julio Montaner and colleagues at the B.C. Centre for Excellence in HIV/AIDS have realized that it is critical to track the virus over time, taking into account the accumulation of mutations even though they may not be present in the most recent sample. (On the other hand, a virus with many mutations may be slightly less virulent, or damaging, than a wild-type virus because

a virus with mutations may be slightly less "fit"—the virus pays a price in its ability to make copies of itself when it picks up mutations.)

New drugs for treatment are continually being developed. We know that it is likely that these new drugs will give rise to new resistance mutations. Strategies for treatment need to keep the viral load completely suppressed for as long as possible. But the good news is that this is already the norm. The majority of PHAs now stay suppressed for years without changing meds. +

Carol Major is a consultant at the Ontario HIV Treatment Network and former head of the HIV Laboratories for the Ontario Ministry of Health.

When Nature Calls

The role of naturopathic medicine for people with HIV

BY DIANE PETERS

IN THE FALL OF 2002, MICHAEL BELL had never felt worse. He'd contracted the Norwalk virus three times, had dropped 60 pounds and could barely get down more than a glass of water and a few soda crackers a day. Diagnosed with HIV in 1993, Bell, 47, had hardly ever been sick. Before contracting Norwalk, he had long been doing well on his HIV meds, was a busy volunteer at a Toronto AIDS organization and was working at his maintenance job.

Never quite having recovered from Norwalk, the following February Bell developed pneumonia and a fever of 109. When he pulled through—just barely—he had less than 50 CD4 cells and a viral load of over one million. “There was nothing the doctors could do for me anymore,” Bell recalls. So he started seeing a naturopathic doctor (ND).

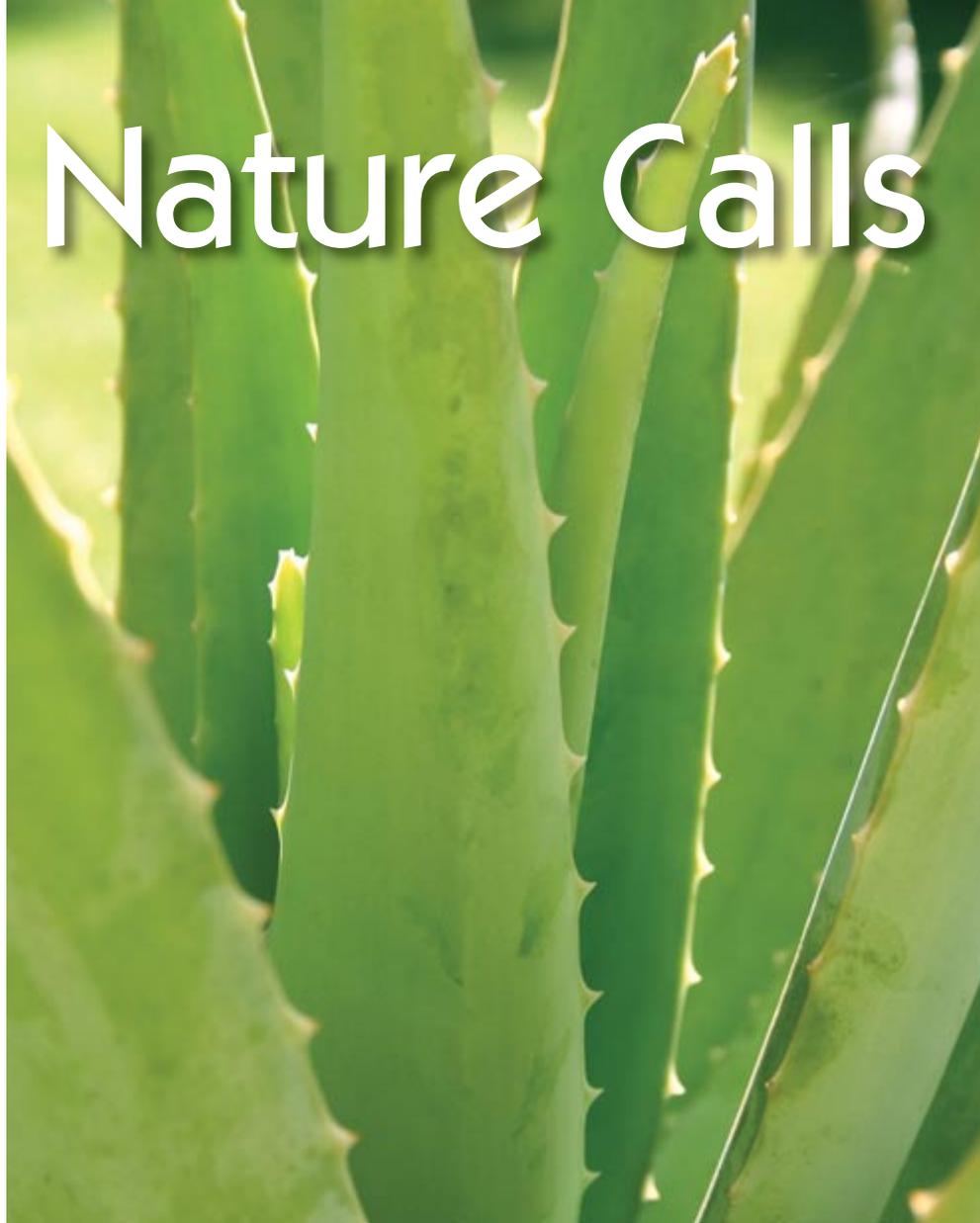
Naturopathic care has become increasingly popular among people with HIV/AIDS (PHAs). And, more often, PHAs go with the support and even the encouragement of their regular doctors, using naturopathic medicine in combination with their medications. There's been a new recognition of the power of naturopathic medicine to help PHAs deal with drug side effects, immunity and some HIV-related conditions, which has led to more HIV clinics offering free naturopathic care. For instance, the British Columbia Persons With AIDS Society (BCPWA) runs a free

clinic in Vancouver and Blood Ties Four Directions Centre offers free naturopathic services in Whitehorse.

Bell was lucky enough to live near the largest naturopathic HIV/AIDS specialty clinic in Canada. At the Sherbourne Health Centre Community PHA Naturopathic Clinic in downtown Toronto, interns—under the supervision of licensed NDS—from the Canadian College of Naturopathic Medicine (CCNM) started treating him, first with acupuncture, a form of Traditional Chinese Medicine that uses tiny needles to help the body's natural energy flow better. When Bell stood up for the first time after having some needles in his pelvis, he felt a tiny shift. “Boy, was I hungry,” he says. “I hadn't been hungry in months.”

Acupuncture is just one of many types of complementary medicine modalities used by naturopathic doctors. Think of them as the general practitioners of alternative medicine. They go to school for four years after completing an undergraduate degree and study an array of treatments including herbs, supplements, homeopathy, Traditional Chinese Medicine (including herbs and acupuncture), nutrition, lifestyle counseling and manual therapies such as massage. In Canada, licensed NDS are trained at either the Canadian College of Naturopathic Medicine in Toronto or the Boucher Institute of Naturopathic Medicine in New Westminster, British Columbia.

Kenn Luby, a Toronto ND who specializes in treating PHAs and works



in the same office as two HIV primary care physicians, says, “A naturopath uses various techniques to tap into the body’s natural ability to heal itself.” To do that, a practitioner looks past surface symptoms—say, a chronic runny nose or fatigue—and finds out about the underlying cause (perhaps inflammation, an imbalance or even something psychological) before planning treatment.

In Bell’s case, one of his biggest problems was all the damage that Norwalk had done to his digestive system: His stomach had shrunk and his bowels and urinary system barely worked, plus he was very dehydrated. Acupuncture, herbs and nutritional supplements encouraged healing, allowing him to start eating and drinking again and to develop smoother digestion. Now, since those underlying problems have been helped, Bell has fewer headaches and a lot more energy and has returned to his volunteer job. He’s still taking highly active anti-retroviral therapy (HAART) but has been able to stop taking other medication to help him eat and sleep. His CD4 count is now up to 170 and his viral load is undetectable.

Like Bell, most PHAs benefit the most from naturopathic medicine when it’s combined with effective HIV treatment. Call it the new combination therapy. “We work very closely with medical doctors. We’re not opposed to regular, allopathic medicine,” says Afsoun Khalili, ND, who works at the Sherbourne Clinic. “There’s nothing like the drugs to bring down the viral load and increase the CD4 count.” What naturopathic medicine can do is help keep the body as healthy as possible and help combat some drug side effects so that people are better able to tolerate their meds.

Some PHAs also use naturopathic medicine as a form of early treatment to help them delay taking meds. Freida Richler did this back in 1988 when she was first diagnosed. She found a rare health care provider—a general practitioner who was also an ND. “I really didn’t want to take drugs because

I’ve always had extreme adverse reactions to them,” Richler says. Dr. Carolyn Dean encouraged her to change her diet (to eat more whole foods and less refined ones) and to take a series of nutritional supplements and vitamins. “For more than 10 years, I relied exclusively on Dr. Dean and other naturopathic doctors.”

Richler, now 47, fared quite well until 1998, when she started running a high fever and lost a lot of weight. After being diagnosed with PCP (*Pneumocystis pneumonia*) and other complications, she began to take HIV drugs. Although she had a hard time with her initial regimen, she eventually adjusted to a simpler combination that was easier to tolerate. Today she has a CD4 count of 1,524 and an undetectable viral load. “I think I responded so well to the drugs and was able to bounce back to relatively good health because I always took large amounts of nutritional supple-

ments religiously, took time for self-care and was careful about my diet,” Richler says.

Richler started to attend the PHA naturopathic clinic in Toronto run by CCNM shortly after recovering from PCP. During her assessment, she mentioned to the naturopathic intern that she hadn’t had a period in more than three years. The intern treated her with acupuncture; in addition to working on meridian points that help support the immune system, she worked on a couple of points that stimulate the reproductive organs. After one month of daily acupuncture, Richler got her period. “Ever since then I’ve had my period regularly,” she says. “That was five years ago.”

PHAs often have a list of health concerns, including side effects, various discomforts and their immune systems. Using just one modality, or more often a combination of two or more, NDs have had success helping PHAs with diarrhea, appetite loss, fatigue, lipodystrophy, stress, hemorrhoids, fissures, weight loss, frequent colds and many other conditions.

But naturopathic medicine has its limits. The treatments at an ND’s fingertips are not strong enough to stop a powerful infection or fight cancer. And NDs themselves debate its impact on immunity. “There certainly are things that can affect the immune system, like sugar and stress,” says Joanne Leung, a Whitehorse-based ND who works at the Blood Ties Four Directions clinic. She admits there just haven’t been the studies to show that naturopathic medicine can actually impact CD4 count or viral load. But, anecdotally, NDs say that their PHA patients end up not just feeling better but with a stronger immune system after treatment. “I believe that the patients who are seeing me as well as seeing their doctors are doing better than those who are following just a medicine regimen,” Luby says.

Along with a lack of good solid medical studies to show exactly what naturopathic medicine can do



LEARN THE LINGO

Acupuncture: A component of Traditional Chinese Medicine that uses very fine needles inserted into special energy points on the body to encourage the body to heal itself.

Botanicals/herbs: The use of plant remedies in the form of supplements, teas or tinctures to treat conditions.

Homeopathy: A form of treatment that uses common diluted remedies to help the body heal itself. The practitioner takes into account a complete patient profile to select an appropriate remedy.

Hydrotherapy: The use of hot and cold water (usually through towels) on various parts of the body to promote circulation and encourage healing.

Nutritional supplements: The use of vitamins, probiotics (healthy bacteria) and other substances normally found in foods in pill form.

Traditional Chinese Medicine: An ancient approach to healing that includes acupuncture and herbs.

NATURAL SELECTION

for HIV, it has a few other flaws. One is that the various modalities impact people differently. For instance, some people respond very well to homeopathy, while others get no help at all.

Interactions with HIV meds can also be a problem. “It’s a real challenge, especially since HIV meds change so rapidly,” says Tasleem Kassam, a Calgary ND who treats PHAs. “Research becomes obsolete so fast.” As a result, many NDs avoid things like botanicals and herbs, as they are the most likely to interact with drugs, while homeopathy, acupuncture and dietary changes are much safer. Luby has another reason for avoiding herbs with his PHA patients. “I don’t want to add to the pharmaceutical load in their bodies,” he says. According to Luby, herbs are really just drugs that come straight from nature.

However, according to Hal Huff, ND, chief supervisor of the Sherbourne Health Centre Community PHA Naturopathic Clinic, herbal medicines, when used cautiously, can be helpful in correcting or managing concerns related to HIV. “Although we know that St. John’s wort and probably other botanical medicines can interfere with HAART, other herbs have been used without any apparent interaction in thousands of patients,” he says. “That said, as with any intervention, we are very careful to monitor for viral load changes or any other evidence of herb-drug interactions.” Huff gives the example of milk thistle, an herb used to protect the liver and treat liver damage. “It’s been the subject of negative attention but it appears to have been vindicated,” he says, citing recent studies that show that milk thistle has no significant impact on the efficacy of antiretrovirals.

NDS develop an individualized treatment plan based upon a holistic assessment of the patient in terms of their physical, mental, social and spiritual health. So it’s no surprise that the start of a relationship with an ND begins with a lengthy consultation. At least an hour long, this discussion is

Want to see a naturopathic doctor (ND)? Here are some tips for making sure you get the best possible treatment:

- **Tell your MD about your ND.** Your medical doctor may be able to help you with a referral. Make sure to get a copy of your most recent lab work over to your ND. Your physician should be kept updated on your naturopathic treatments to help monitor for drug interactions and other possible problems.
- **Look for qualifications.** Make sure your ND has graduated from a reputable school and has taken either the North American or provincial licensing exams.
- **Ask about HIV.** Ideally, find an ND who has treated PHAs before. If that’s not possible, ask your ND to consider talking to a naturopathic HIV expert to help with your treatment.
- **Follow your gut.** If you’re not comfortable with your treatment regimen or you fear you’re not getting the right care, trust your instincts to either make suggestions or switch to another practitioner.



about sharing medical information (meds, medical history, side effects, preexisting conditions and the like) and personal information. Emotional health, stress level and family history all play into a person’s treatment. “I end up knowing more about patients than their own mother does,” Kassam says. In the initial assessment, NDs also perform a thorough physical examination.

That’s where naturopathic medicine’s true power lies—in its ability to treat the whole person, not just their disease or their numbers. And that’s very important because naturopathic medicine often takes a lot of effort on the part of the patient. “It’s hard work and it’s not for everyone,” Leung says. To make naturopathic medicine work, a patient must often make dietary

changes, take supplements and herbs on a regular schedule, show up for regular appointments and even deal with emotional issues.

PHAs must also be patient with naturopathic medicine: It’s not a quick fix. “It takes time, a lot longer than I thought,” Bell says. He’s still getting weekly acupuncture treatments to keep his health and particularly his digestion strong.

Just as an ND picks a mix of modalities to suit each patient, so must they adapt treatment to what a patient can handle. This is true patient-centred care: No one should have to do acupuncture if they’re really uncomfortable with needles, or be turned away from naturopathic care if they can’t afford the supplements or are unable to make dietary changes. “It fits in where the clients want it to fit in,” Leung says. When an ND and patient work closely together to create a treatment program and it works, it’s worth the effort. “It can be very empowering to make some changes and see some results,” she adds.

As more free naturopathy clinics and services open up for PHAs and as more doctors embrace complementary medicine, more PHAs are benefiting from naturopathic care. It’s a nurturing approach that can help with many problems that cause discomfort and even long-term damage. “I see the future of medicine being naturopaths and conventional doctors working together, especially with HIV but with any condition,” Khalili says. “The two work best together.” Freida Richler adds: “We need more naturopathic doctors who are familiar with drugs and more medical doctors who practice integrative medicine.” +

Diane Peters is a Toronto-based writer who has written extensively about health, including HIV/AIDS, for *Chatelaine*, *Reader’s Digest Canada*, *POZ* and *Today’s Parent*.

For more information, check out CATIE’s Practical Guides to Complementary and Herbal Therapies for People Living with HIV at www.catie.ca or by calling 1.800.263.1638.

Here's Lookin' at You, Kidneys

HIV and kidney disease— what you need to know

BY MAGGIE ATKINSON

FOR NINE YEARS, MY MOTTO was: “If it ain’t broke, don’t fix it.” That’s why, despite worsening lipodystrophy, I clung to the drug regimen that was keeping me alive.

Why mess with success? Though my viral load was still below detection, my doctor was urging me to make a change. She wanted me to replace d4T (Zerit) with tenofovir (Viread) because of increasing evidence that d4T was responsible for my sunken cheeks and stick-like arms and legs. Even more sinister, it could be causing damage not apparent to the human eye.

So, why hadn’t I made the switch? I was concerned about safety. Tenofovir, a nucleotide analogue, is a member of a family of drugs known to cause kidney damage. A related drug, adefovir, was denied approval by the U.S. Food and Drug Administration (FDA) for treatment of HIV because of kidney problems. Although tenofovir was approved by the FDA and Health Canada based on clinical trials that showed no significant kidney problems, I am cautious about drugs.

I’ve had HIV since 1984 and have seen initial enthusiasms for drugs dissipate when adverse events, not apparent during clinical trials, appeared once the drug was approved and used by thousands of people. I remember in 1997 when we first discovered

lipodystrophy in people with HIV/AIDS (PHAS) on protease inhibitors, a year after PHAS started using these drugs. So, until a drug has been on the market for a few years, I feel rather leery of it. But as the evidence mounted that tenofovir could be a safe replacement for d4T, I decided to make the switch. Many PHAS may now be on tenofovir because the latest treatment guidelines recommend it as part of the nuke backbone of antiretroviral therapy.

Before I began to take the new drug, I consulted my naturopath, Kenn Luby. He treats many PHAS in his Toronto practice and has helped me tremendously over the years. He made some changes to the supplements I take each day and, with that, I felt more confident starting tenofovir.

But only a few weeks later, I read an e-mail from NATAP, the National AIDS Treatment Advocacy Project, which concerned me. At the Conference on Retroviruses and Opportunistic Infections (CROI) in Boston last February, some researchers questioned how we measure kidney function and the rate of kidney dysfunction caused by HIV, tenofovir and other nukes. By only testing serum creatinine, as we currently do, we may be missing some PHAS—especially women and those over 50—who are at risk for chronic kidney disease. I decided to find out what I could do to protect my kidneys.



THE URINARY TRACT

Every day the kidneys filter about 200 litres of blood. From this, about two litres of urine flow through the ureters to be stored in the bladder. The urine is ejected from the bladder and out of the body through the urethra. The male urethra ends at the tip of the penis; the female urethra ends just above the vaginal opening.

THE KIDNEYS

We have two kidneys—located in the back, one on either side of the spine, below the ribcage. They're about the size of a fist and are shaped like kidney beans. Each kidney has about a million tiny blood-filtering units called nephrons. In each nephron, a network of tiny blood vessels called the glomerulus attaches to a small tubule. Blood is filtered in the glomerulus, and extra water and waste pass into the tubule and become urine.

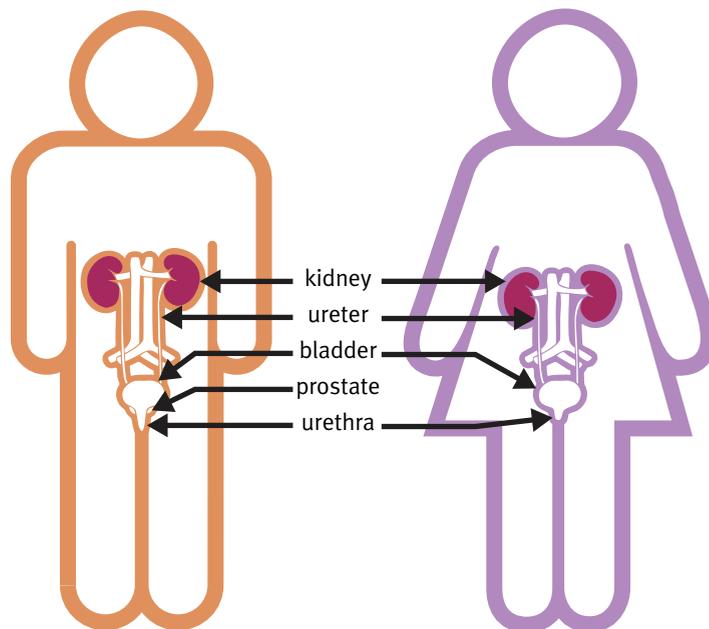
I was under the impression that kidneys just cleaned the blood, but they do a lot more than that. The kidneys have four main functions:

1. They balance body fluids.
2. They balance body chemicals (ions or minerals), such as potassium, calcium, phosphorus and magnesium.
3. They remove waste products, like urea (from the breakdown of protein from food) and creatinine (formed by normal muscle activity).
4. They produce the following essential hormones:
 - erythropoietin (EPO), which helps make red blood cells,
 - renin, which regulates blood pressure, and
 - the active form of vitamin D (D₃), which helps maintain calcium for bones.

KIDNEY DAMAGE

These are three different kidney-related problems that can affect PHAS. Their causes and treatments vary:

1. **Kidney stones** result from the build-up of crystallized salts and minerals, such as calcium or drugs like indinavir (Crixivan), in the urinary tract. If kidney stones are large enough



to block the kidney or ureter, they can cause severe abdominal and/or back pain. The stones usually pass through the urinary tract on their own, but in some cases they may need to be removed surgically. About 8% of people taking indinavir may get kidney stones. Fortunately they do not often cause kidney disease. Drinking lots of water can be helpful for preventing kidney stones and helping them to pass.

2. **Urinary tract infections (UTIs)** occur in a part of or throughout the urinary tract, but mainly in the bladder and urethra. If left untreated or if they happen repeatedly, UTIs can travel up the ureters from the bladder and affect the kidneys. UTIs are usually caused by intestinal bacteria, such as *E. coli*, which are found in feces (poo). Women are more likely to get UTIs because they have shorter urethras than men. Sex, even with a condom, can transfer the feces to the urethra. Drinking lots of water and 8 ounces (240 ml) of cranberry juice cocktail a day (preferably at least 27% juice) and wiping from front to back after a bowel movement can help prevent UTIs.

3. **Fanconi's Syndrome**, sometimes caused by tenofovir, results in acidosis, loss of electrolytes, high creatinine levels and renal insufficiency. It can take months to recover, and, in some cases, kidney function may not return completely to its pre-treatment level. The best way to avoid it, according to

Dr. Michelle Hladunewich, a kidney specialist from Sunnybrook and Women's College Health Sciences Centre in Toronto, is to ensure that the dosage of tenofovir is adjusted appropriately before starting the drug. She says that kidney function, electrolytes, calcium profile and a urinalysis should be monitored every 3–4 months. "The key is to better judge renal dysfunction at the outset at least by utilizing one of the equations to estimate GFR (glomerular filtration rate) or by obtaining a creatinine clearance on a 24-hour urine collection."

All of these kidney problems can lead to kidney disease.

Kidney diseases usually damage the nephrons and cause them to lose their filtering capacity. Kidney disease can be acute or chronic. Acute kidney failure can result suddenly from poisoning, infection or trauma. A gradual loss of kidney function, over years or decades, is called **chronic kidney disease (CKD)**. If left untreated, kidney disease can result in impaired kidney function and, ultimately, kidney failure.

The rest of this article deals with chronic kidney disease, which is becoming increasingly more prevalent among PHAS.

CAUSES OF CKD

Chronic kidney disease is defined as kidney damage (as evidenced by protein in the urine) or decreased

kidney function (as evidenced by reduced GFR) for a period of three months or more. It is a condition caused by various diseases. According to the Kidney Foundation of Canada, as many as 1.9 million Canadians may have CKD but most are unaware of it.

The two most common causes of CKD are **diabetes** and **high blood pressure**. Some other causes are listed below:

- The third most common type of kidney disease is **glomerulonephritis** (inflammation of the glomeruli and the kidney)—a group of diseases in which the immune system mistakenly attacks the glomeruli.
- **Inherited diseases**, such as polycystic kidney disease, which causes large cysts to form in the kidneys.
- **Reflux nephropathy**. Some people are born with an abnormal junction of the bladder and the ureter, which causes urine to flow back up to the kidney. This causes infections and scarring of the kidneys, which can lead to kidney failure.
- **HIV** and other diseases that affect the body's immune system. HIV-associated nephropathy usually begins with heavy proteinuria (large amounts of protein in the urine) and progresses rapidly (within a year of detection) to end-stage renal disease if left untreated.
- **Obstructions** caused by kidney stones, tumours or an enlarged prostate gland.
- **Repeated urinary tract infections**.
- **Unresolved acute kidney failure**.
- **Drugs**. Long-term or heavy use of painkillers and anti-inflammatories, such as acetaminophen (Tylenol), acetylsalicylic acid (Aspirin), ibuprofen (Advil, Motrin) and naproxen (Aleve, Anaprox). Combining these meds with caffeine

can further damage your kidneys. **Street drugs** such as heroin, cocaine and amphetamines can also cause kidney damage.

DIAGNOSIS OF CKD

In the later stages of kidney disease, people may have some of the following symptoms:

- more fatigue
- less energy
- trouble thinking clearly
- poor appetite
- trouble sleeping
- dry, itchy skin
- muscle cramps at night
- swollen feet and ankles
- puffiness around the eyes, especially in the morning
- a need to urinate more often, especially at night

However, there are usually no symptoms of kidney disease until the damage is severe. That is why it's important to be tested.

TESTING FOR CKD

According to Dr. Hladunewich, everyone with HIV/AIDS should be screened yearly for kidney disease because PHAs are "proving to be a fairly high-risk group." The first step is a blood test for serum creatinine and a urine test to measure protein (for the albumin:creatinine ratio). These tests are used to assess both kidney damage and kidney function.

Kidney damage is measured by the amount of protein in the urine, because when the kidneys are damaged, protein leaks into the urine.

Measuring **kidney function** is more controversial. Doctors and researchers normally use the serum creatinine test to measure kidney function indirectly, but a study presented at CROI suggested that this test alone might not be sufficient. Instead, the creatinine test result should be used in a mathematical equation, along with age, race and gender, to calculate the estimated glomerular filtration rate (estGFR)—an estimate of how well the glomeruli are filtering. Sometimes you also read about the creatinine clearance rate, a similar test of kidney function.

The National Kidney Foundation is concerned that many people may be in the early stages of chronic kidney disease (CKD) and not know it. It recommends that adults who are at risk for kidney disease use the calculator on its website to determine their estGFR. This calculator is a screening tool to inexpensively identify people at risk for CKD. estGFR is not an absolute lab test result; it's only an estimate of kidney function.

Unless you live in B.C., where the labs now provide the GFR result, you can ask your doctor to calculate your estimated GFR. Or, if you know your creatinine level, you can use the GFR calculator (www.kidney.org/professionals/kdoqi/gfr_calculator.cfm). It uses an abbreviated form of the MDRD equation. Fill in your creatinine test result, age, sex and race to estimate your GFR. Check the box for "umols/l" when inputting your creatinine level because that's the international system unit used in Canada to measure creatinine.

If your estGFR measures less than 60, discuss your results with your doctor.

There are two well-known equations used to calculate estGFR in adults—Cockcroft-Gault and the MDRD Study. San Francisco researchers compared serum creatinine to estGFR (using the MDRD Study equation) in more than 1,600 patients in CHORUS, a large, observational U.S. cohort. Using the serum creatinine test, none of the 136 women in the study showed kidney dysfunction, but using the estGFR equation, 10 (7%) of them had moderate kidney disease. Also, among the 307 people over 50 years old, the creatinine test results indicated that 12 (4%) had moderate kidney disease—the estGFR showed that 66 (21%) did. Overall, using the creatinine test, 1.9% of patients showed moderate kidney dysfunction, while that figure increased to 13.8% with estGFR. The take-home message: Perhaps we should be using the estGFR measurement in studies and in the clinic.

If these initial lab tests indicate kidney damage or reduced kidney function, the doctor may recommend an ultrasound or X-ray to see whether the shape or size of the kidneys is

LEARN THE LINGO

Doctors who specialize in kidney problems are called **nephrologists** (from the Greek word for kidney, *nephron*).

Doctors who specialize in problems of the organs and tubes that transport urine from the kidneys to outside the body are called **urologists**.

Anything related to the kidneys may be called **renal**, from Latin *renes*, meaning kidneys.

abnormal. A CT-scan or MRI might also be done. These tests are called renal imaging. The doctor may also do a kidney biopsy—a procedure in which a needle is used to extract small pieces of tissue from the kidneys for examination under a microscope.

Certain people may need additional testing, such as a 24-hour urine collection, if they're over 70, very thin, obese or vegetarian, or if they take certain drugs, like Bactrim/Septtra or cimetidine (Tagamet) because these drugs can affect your serum creatinine levels. Excessive exercise or taking creatine supplements may also increase serum creatinine levels.

In the final stage—end-stage renal disease—the kidneys stop working and dialysis or a transplant is needed. Dialysis involves using a machine or other artificial device to remove the excess water and wastes from the body. Organ transplants are rarely performed on PHAs in Canada, although they are done in the U.S.

TREATMENT OF CKD

Medication, diet, supplements, exercise and drug dosage adjustments may help prevent or delay kidney

failure. The treatment will depend on the stage of kidney disease, the cause, symptoms and other health problems.

MEDICATION

There isn't a medication for CKD. You can only treat the causes and the symptoms. For example:

- If you have high blood pressure, one of the causes of CKD, your doctor may recommend blood pressure medication.
- If you have anemia, which can be brought on by kidney disease, you may need synthetic epoetin (EPO) or iron.

DIET

According to Diana Johansen, dietician at the Oak Tree Clinic, the Women and Family HIV Centre for British Columbia, when a person has normal kidney function their diet is generally not adjusted to prevent kidney disease.

When the kidneys are unable to function properly, various substances build up in the blood to undesirable levels. Dietary changes aim to reduce the intake of foods that create more of these substances. In the early stages,

you may need to reduce the amount of protein, phosphorus and sodium in your diet. Later on, in advanced kidney disease, you may also need to reduce potassium and fluids. Speak with your doctor or a renal dietician before making any changes to your diet.

- Protein is found in meats, dairy products, dried beans, soy products and nuts.
- Dairy products, dried beans and peas, nuts, soft drinks, cocoa and beer are high in phosphorus.
- Since sodium can raise your blood pressure, you may need to cut down on salt and canned, pickled or processed foods. Avoid salt-substitutes that contain potassium.
- High sources of potassium are bananas, dried fruits, orange juice, melons, dried beans, nuts, potatoes and tomato sauces. In advanced kidney disease, high potassium levels can affect the heart rhythm.
- High blood cholesterol levels can also be associated with kidney failure. A low-fat diet, exercise and lipid-lowering medications can help reduce cholesterol levels.

I wondered about water intake. Dr. Hladunewich warned that too much water could be dangerous for someone with significant kidney disease. It's best to determine your kidney function through the appropriate testing measures. If you have reduced kidney function, you may need to consult a renal dietician as well as a nephrologist for advice about your diet. Even something that might normally seem harmless, like drinking water, can potentially pose problems if your kidneys aren't working properly. That said, as long as your kidneys are functioning normally, you should make sure to get enough water every day.

SUPPLEMENTS

Lark Lands, a medical journalist and longtime AIDS treatment educator and advocate, says there isn't any "magic bullet" for supporting the kidneys but there are some basics that can help. Here are her recommendations:

- The very minimum that every PHA should take is a multivitamin, an

STAGES OF CHRONIC KIDNEY DISEASE

Based on the kidney damage and kidney function tests, CKD is divided into five stages. Not all people progress from Stage 1 to Stage 5. If you have any of the risk factors below, you may be at increased risk of developing chronic kidney disease and should be tested for it.

Stage	Description	Glomerular Filtration Rate (GFR)
At increased risk	Risk factors for kidney disease: diabetes; high blood pressure; family history; age over 50; ethnic origin Aboriginal, Asian, South Asian, Pacific Island, Caribbean, African or Hispanic; being HIV positive	More than 90
1	Kidney damage (protein in the urine) with normal kidney function (estGFR)	More than 90
2	Kidney damage (protein in the urine) with mild decrease in kidney function (estGFR)	60 to 89
3	Moderate decrease in kidney function (estGFR) with or without kidney damage (protein in the urine)	30 to 59
4	Severe decrease in kidney function (estGFR)	15 to 29
5	Kidney failure or end-stage renal disease (dialysis or kidney transplant needed)	Less than 15

(adapted with permission from the National Kidney Foundation)

antioxidant formula and anti-inflammatory fish oil.

- Take plenty of antioxidants. All the things that protect you against heart disease also help protect the blood vessels in the kidneys. Examples of antioxidants: vitamin E, vitamin C, bioflavonoid complex, carotenoid complex, selenium, N-acetyl-cysteine (NAC), coenzyme Q₁₀, alpha-lipoic acid.
- Take plenty of natural anti-inflammatories. Inflammation plays a key role in the artery-damaging and -blocking process. By countering that, you may also help prevent kidney problems due to scarring and blocking of the tiny blood vessels. Avoid fats that promote inflammation, such as partially hydrogenated oils (“trans fats”) and polyunsaturated vegetable oils. Here are some examples of naturally anti-inflammatory foods and seasonings: garlic, ginger, curcumin, bioflavonoid-rich fruits like dark berries, and omega-3 fatty acid-rich foods like fatty fish, flaxseed and walnuts. (Garlic may interact with some drugs, so speak with your doctor about possible interactions with your meds.)
- Protect yourself against the blood sugar effects of HIV and HAART because elevated blood sugar can damage the kidneys over time. Nutrients that help maintain normal cellular insulin sensitivity and improve glucose tolerance may help, such as alpha-lipoic acid, the B vitamins (especially B₆) and the minerals chromium and zinc.

EXERCISE

With your doctor’s permission, start a regular exercise program that includes strength, flexibility and cardiovascular training. Exercise is important, especially when you’re HIV positive and on antiretroviral therapy, for many reasons, including:

- It may prevent or help with diabetes, high blood pressure, heart disease, chronic kidney disease, cancer, osteoporosis and arthritis.
- It can help ease restless leg syndrome, sometimes associated

with kidney disease.

- It will help to get rid of excess fluid and toxins through the skin.

DRUG DOSAGE ADJUSTMENTS

You may need to change your drug dosages. Septra/Bactrim, tenofovir and the nucleoside drugs (except abacavir/Ziagen) might need to be reduced. Oddly enough, although indinavir can affect the kidneys, it is not metabolized through the kidneys, so dosage adjustments are not required.

Some drugs that may harm the kidneys:

- tenofovir (Viread) – for treating HIV; there is some early evidence that combining tenofovir with ddI (Videx) may be related to more kidney damage than tenofovir alone
- Hepsera – for hepatitis B
- cidofovir (Vistide) and foscarnet (Foscavir) – for CMV retinitis
- IV pentamidine – for PCP treatment
- aminoglycosides – a class of antibiotics for serious infections (includes Amikacin, Gentamicin)
- rifampin – for tuberculosis
- acyclovir (Zovirax) and valacyclovir (Valtrex) – for herpes and shingles
- NSAIDs (non-steroidal anti-inflammatory drugs), such as acetylsali-

cyclic acid (Aspirin), ibuprofen (Advil, Motrin), acetaminophen (Tylenol)

- Septra/Bactrim – for PCP prevention or treatment
- If you are taking more than one of these drugs at a time, it’s a good idea to have your kidney function monitored more often.

THE KIDNEYS ARE ALL RIGHT

After learning about what can go wrong with the kidneys, I was nervous about my first checkup three months after starting tenofovir. But everything was fine. My creatinine level was slightly higher than when I started, and when I took that result and calculated my estGFR it was 89, which is only a mild decrease in kidney function. There’s no protein in my urine, so I don’t have kidney damage. I don’t have kidney disease but I’ll need to be checked every few months. In the meantime, I’ll do what I can to prevent diabetes, high blood pressure and high cholesterol, and to protect my kidneys. Here are some things you can do to protect yours:

- Have your blood pressure, urine and blood (including creatinine and cholesterol) checked regularly.
- Control high blood pressure (it should usually be less than 130/80).
- Try to quit or cut down on smoking.
- Exercise regularly.
- Maintain a healthy weight.
- Avoid excess alcohol (more than one drink a day).
- Avoid street or recreational drugs.
- Get enough sleep.
- Avoid heavy or long-term use of painkillers (low-dose Aspirin for heart disease is OK).
- If you have diabetes, maintain good control of your blood sugar. +

Maggie Atkinson is the former co-chair of AIDS ACTION NOW! and the founding chair of Voices of Positive Women in Toronto. She has been HIV positive for more than 20 years and takes a positive and holistic approach to maintaining her health.



THE KIDNEY CONNECTION

The National Kidney Foundation

www.kidney.org

The Kidney Foundation of Canada

www.kidney.ca

The National Kidney Disease Education Program

www.nkdep.nih.gov/index.htm

Life Options www.lifeoptions.org

(sponsored by Amgen Inc., which markets a number of products in the field of nephrology)

Kidney School www.kidneyschool.org

(also sponsored by Amgen Inc.)

HIV InSite www.hivinsite.com

(search for “renal”)

Lark Lands’ Positively Well

www.larklands.net (see Treatment Fact Sheets)

NATAP www.natap.org

KidsHealth www.kidshealth.org

CATIE Fact Sheet on tenofovir (Viread)

www.catie.ca/facts.nsf



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POTTERY BARN

Henry “Blake” Hiebert on the healing qualities of clay

I LOVE THE WAY CLAY FEELS IN MY hands. Working with clay is very spiritual and therapeutic. I don’t know what’s in it, but clay makes you feel magical.

For 21 years I taught pottery at the Carnegie, a community centre at Hastings and Main, a rough area of Vancouver. It’s called the “living room” for the downtown eastside and it’s for low-income, marginalized people. But last year I left because everyone was passing away like flies in that area of town. I don’t have enough fingers or toes to count how many friends passed away. I was lonely and depressed.

I don’t tend to make new friends now because I’m afraid they won’t live long. I spend most of my time at home doing pottery. This is my peace and quiet. When I get into the clay, I tend to forget about AIDS, it kind of just fades away.

In 1995, my partner, John, took notice of me having cold sweats, losing weight and being sick a lot. He diag-

nosed me before the doctor did. After my HIV test, I waited for two weeks on pins and needles because John already had it. When the doctor called me into the office, he told me my CD4 count was down to 40. I had full-blown AIDS and MAC (*Mycobacterium avium* complex). I thought that was the end of the road for me. But I took pills for the MAC and got better.

Back then with two partners in one household with full-blown AIDS, it was always something. Sheer survival took over. Now I’m on meds and I’m pretty active. I live with HIV, but I never go too far into the future. For years John and I were living in one-month intervals. Now with treatment and all, we have a three-month horizon. Every three months, you shed your skin, like a snake. I find this very optimistic.

Now I teach at the Gathering Place, across the street from BCPWA. We’ve



got a terrible crystal meth problem in Vancouver and this community centre is in the eye of the hurricane. It’s full of street people, and a lot of the students have HIV.

My students call me Blake, even though my real name’s Henry. A friend of mine, a numerologist who died of AIDS, once said to me: “Don’t ever go by Henry. They all die of diseases. Think of Henry VIII, he died of syphilis. Go with your middle name.” So my art name is Blake.

All my students know I have HIV. We have our own little support group.

We talk about our health, our meds, what we’re being diagnosed with. We share our stories. There’s lots of laughter and jokes. Clay makes you want to talk about things. There’s a lot of sexual talk some-

times, especially among the gay guys. I tell them to try to respect everyone in the class, because there are straight people, too. The only things I ask them not to discuss are politics and religion because things can get heated and there are people in the class from all different backgrounds.

When people come into the class, they’re usually depressed, but after three weeks they have this happy, beautiful face on them. Memories come up when you knead the clay. A lot of people think of their moms because when they start digging their hands in the clay, they remember their mothers baking, rolling out the dough.

When we do the glaze and kiln firings, everyone says it’s like Christmas. They’re like kids at a bakery. After their work comes out, I do little critiques, in a positive way.

Pottery has helped me grow and I like to see other people grow just as much as I have. That’s my reward. I have all these people around me who give me support, and it feels good to give something back. +



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